

**Genomics Education for Public Health:  
A Resource Guide for Curriculum Development**

by

Linda J. Dawson

April 10, 2005

A Master's paper submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Public Health in the School of Public Health, Public Health Leadership Program.

Approved by:

Content Reader: Elizabeth Balkite, MS, CGC

Elizabeth A. Balkite

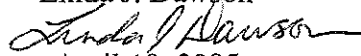
Second Reader: William Williamson, MPH

William Williamson MPH

**Genomics Education for Public Health:  
A Resource Guide for Curriculum Development**

by

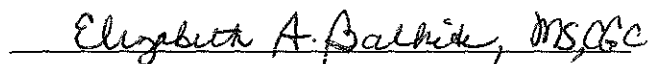
Linda J. Dawson

  
April 10, 2005

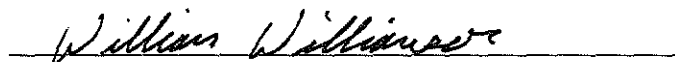
A Master's paper submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Public Health in the School of Public Health, Public Health Leadership Program.

Approved by:

Content Reader: Elizabeth Balkite, MS, CGC



Second Reader: William Williamson, MPH



**Abstract:** Genomics has been identified by the Institute of Medicine (IOM) as one of eight new emerging areas critically important to building public health infrastructure and capacity in workforce development initiatives. The completion of the human genome map in 2003, creates new possibilities for the public health workforce to respond to these new scientific advances. A number of genomic competencies have been developed with dialogue among interdisciplinary teams representing various organizations. These competencies were developed in an effort to ensure a basic level of needed competence in genomics in practice and training of the public health workforce. With appropriate training, the role of genomic influences may be woven into existing knowledge of environmental, behavioral and lifestyle factors and applied to an improved understanding of the risks of disease predisposition and acquisition. Many of the top ten causes of death in the United States are potentially preventable, with nine having a known genetic component. One of the challenges for the public health educational system as discussed herein is to train new students as well as the existing workforce in the applications of genomics to population health in order to achieve its remit of improving health and preventing disease. The uptake of genomics into public health practice will take place in the context of a variety of potential impact factors which will be considered along with acknowledgement of shrinking budgets for public health services, programs and education. The public health community must avail themselves of freely available existing educational resources in genomics and forge new partnerships to assure the appropriate education and training is taking place. The Genomics Competency/Resource

Project described here is one such initiative to make use of these existing electronic resources and match them with competencies and associated learning objectives customized for public health personnel with no background in genetics. This Resource Guide is primarily intended to be used to aid in curriculum development but is not limited to that purpose as anyone with an interest in genetics can benefit from the competencies, learning objectives and resources described.

**Background:** Genetics has traditionally been relegated to the domain of highly specialized practitioners because single gene and chromosomal disorders such as Huntington's disease, Down's syndrome, various newborn disorders and others were uncommon, affected relatively few individuals and no real prevention or treatment interventions existed. These disorders did not significantly attract the attention of the broader medical community and even less so for the public health community whose remit is primarily disease prevention with a population health focus. However, the epidemiologic transition has occurred and chronic disease is increasingly the culprit for the major causes of mortality and disability as the population continues to age. With the mapping of the human genome completed ahead of schedule in April 2003, the single gene disorders have given rise to new possibilities for unraveling the complexities involved with multiple gene and environmental influences on disease predisposition and acquisition.

With shrinking federal, state and local budgets for public health activities, prevention efforts represent a less costly alternative compared with treatment interventions and disease management initiatives traditionally practiced by the

medical care community. The mapping of the human genome represents a starting point to begin to reveal a more relevant understanding of the genetic influence of disease and the multitude of potential interacting variables.

With nine of the top ten causes of mortality in the United States having a significant known genetic component, an opportunity exists for public health to begin to integrate genomic advances into prevention strategies in which environmental, behavioral and lifestyle factors are increasingly playing key contributory roles. A combination of environmental factors and individual behaviors has been estimated to account for 70% of all premature deaths.<sup>1</sup> Both of these factors clearly fall within the domain of public health practice and responsibility. Integrating knowledge of gene-environment interactions with genetic predisposition to certain behaviors and disease susceptibility could provide new insights into counseling and health behavior/health education practices. A new kind of interdisciplinary dialogue is needed among scientists, geneticists, ethicists, lawyers, clinicians, the public, policymakers and the public health community. New roles and partnerships must be forged to inform decision-making using genomics to improve health and prevent disease. However, like many other technological advances, they take time to transition from bench to bedside, and they can either be used for the good of or to the detriment of society. The checks and balances of interdisciplinary teams are more important now than ever before.

The ecological or health field model put forth by Evans and Stoddart<sup>2</sup> and endorsed by public health leadership, is key within which to fit the discussion about a number of influences of genomics on public health workforce development. Some of these influences include the directives put forward by the Institute of Medicine (IOM), a description of the public health workforce and functions, educational initiatives undertaken by schools of public health, health policy issues, the genomics information explosion and the influence and reach of the internet and the media. Finally, no discussion is complete without consideration of budgets and resources necessary to adequately carry out public health activities. Each of these influences will be discussed to provide a context within which to discuss genomics and public health practice.

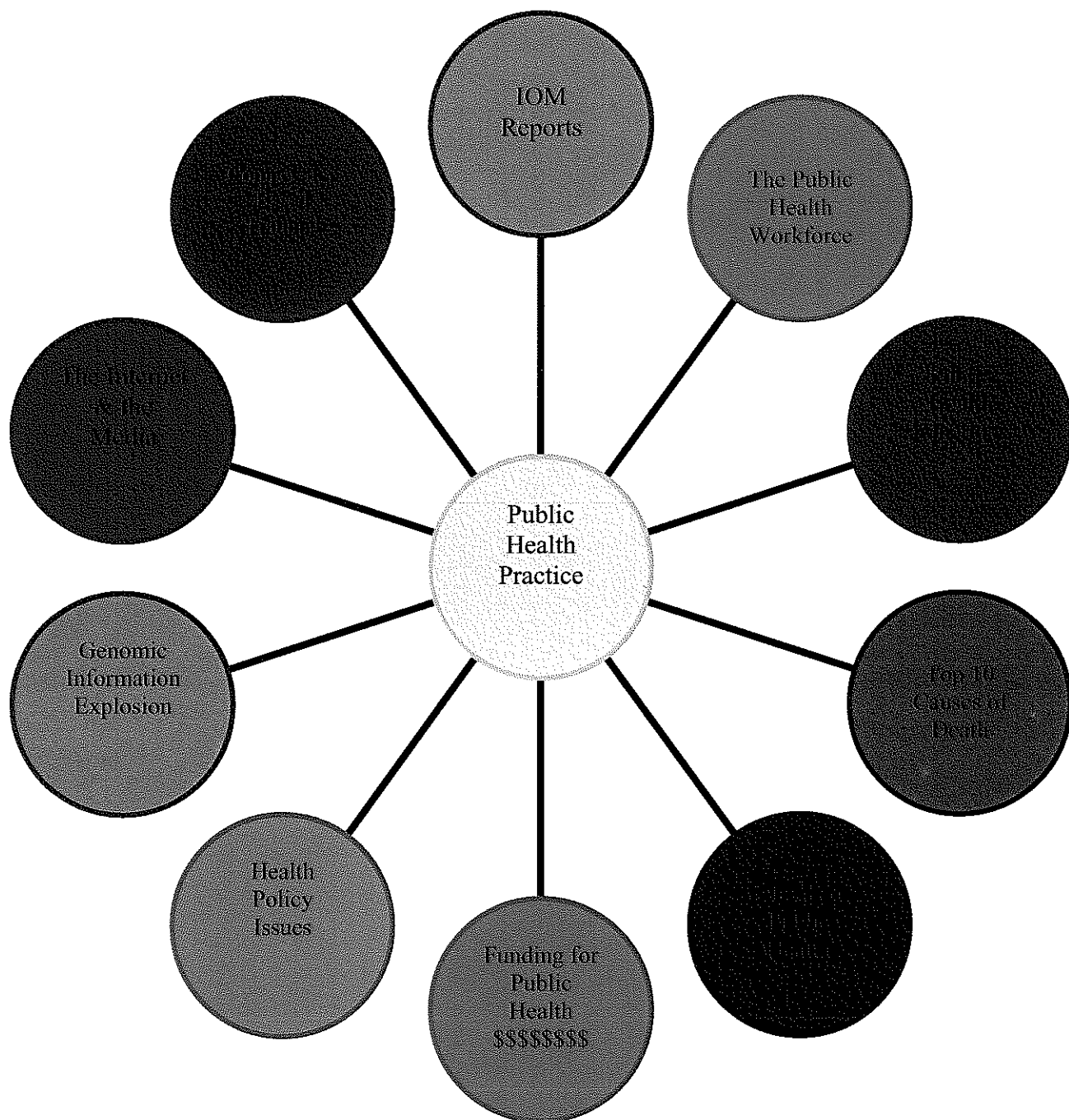
### **The Ecological Model in Public Health Practice**

Public health has traditionally focused on prevention and risk reduction strategies to improve health and prevent disease with a population focus, while the medical system has primarily focused on identification, diagnosis, treatment and/or amelioration of existing disease focusing on the individual patient. The knowledge of genomics adds more specific information to the armamentarium of tools to help influence behavioral and lifestyle modifications and their impact on disease risk and acquisition. **Appendix 1** depicts a visual model of the determinants of health from a public health perspective<sup>3</sup> and **Appendix 2** visually depicts these determinants in a manner in which the consumer may readily recognize.<sup>4</sup>

Historically the debate revolving around disease causation has been nature vs. nurture, but a transformation has evolved that places the multiple determinants of health not in an adversarial “either or” role, but in a larger context in which complementary influences such as genetic predisposition, environment and lifestyle factors all contribute to the risk of disease acquisition. Although public health cannot influence individual genetic makeup, knowledge of the prevailing principles and applications of genomics can serve as the initial step in applying strategies and developing programs and policy options that address the assurance function of public health. A more complete understanding of the impact and magnitude of interactions between genetics, environmental and lifestyle factors on disease acquisition is necessary to ensure that the development of prevention strategies on health outcomes are targeted and sustainable.

The traditional ecological model is a pervasive influence in many aspects of public health practice. **Figure 1** represents the author’s perspective of an adapted ecological model and focuses on some key factors that can influence the uptake and utilization of genomics in public health practice. Each of these influences will be discussed consecutively in a clockwise manner beginning with the IOM Reports.

**Figure 1: An Adapted Ecological Model: Impact Factors Influencing the Uptake of Genomics in Public Health Practice**





## **Institute of Medicine Reports, Recommendations & Call to Action**

Since the 1988 landmark report on the state of public health published by the Institute of Medicine (IOM)<sup>5</sup> several follow-up and companion reports have been released emphasizing the need to improve and reform public health infrastructure and education.<sup>6,7,8</sup>

A national agenda for public health workforce development has been put forward that includes genomics as one of eight new emerging areas.<sup>6</sup> Although genomics is only one of these new areas highlighted by the IOM, this knowledge area transcends the other emerging areas in multiple ways. By focusing on genomics as an educational initiative, other areas can also be addressed in this context such as medical informatics, communication, policy, cultural competence, global health and others.

In addition, a companion report issued by the IOM in 2003 described the educational goals for public health professionals for the 21<sup>st</sup> century.<sup>8</sup> The call to action includes emphasizing the central role of the ecological model of health which considers multiple influences on health such as social, economic, cultural, environmental, lifestyle, individual genetics and biology of health and disease.<sup>8</sup> The IOM reports also emphasize the roles of schools of public health in educating the educators, serving as a central point for transdisciplinary research and teaching especially with medical and nursing schools, improving health literacy, contributing to health policy, collaborating with other professional schools,

engaging the community and assuring access to lifelong learning for the public health workforce. Recommendations for the roles of federal, state and local public health agencies are also outlined in the IOM reports. Key roles include:

- Assessment of public health workforce developmental needs
- Assurance that appropriate personnel, with MPH level education are filling governmental public health leadership and management roles
- Providing increased funding for curriculum development
- Academic/practice partnerships
- Increase participation of public health professionals in educational activities of schools of public health

Genomics is one of the continually evolving areas in which all of these recommendations can be integrated to help educate the public health workforce. It represents a new lens through which public health practitioners can view the multiple determinants of disease and apply this knowledge to population health.

In response to this national call to action, the Office of Workforce Policy and Planning at the Centers for Disease Control and Prevention (CDC) has undertaken several key initiatives and has assumed a key organizational role in public health workforce development initiatives.<sup>9</sup> The mission of the Office of Workforce Policy and Planning is “to improve the ability of public health workers, nationwide, to perform the essential services of public health and to prepare the workforce to respond to current and emerging health threats. The Office of Workforce Policy and Planning enhances the ability of the workforce to perform essential public health services through programs such as: Workforce Development Strategic Plan, Leadership Development, Academic Partnerships, Center for Public Health Preparedness, and Public Health Ready.” A strategic

plan for workforce development which arose from this initiative, has focused on six major strategies to accomplish their goal:<sup>9</sup>

1. Monitor Workforce Composition
2. Identify Competencies/Develop Curriculum
3. Design Integrated Learning Systems
4. Use Incentives to Assure Competency
5. Conduct Evaluation and Research
6. Assure Financial Support

In support of these strategies, the CDC website has compiled a workforce development library covering the past decade of training, planning and policy initiatives as well as competencies developed by consensus for specific areas of public health practice. These areas include: medical informatics, maternal and child health, environmental health, law, genomics and many others.

### **The Public Health Workforce**

A public health professional is defined as a person educated in public health or a related discipline employed to improve health through a population focus. The public health “workforce” or practitioners include all those involved in the practice of public health. However, many of those considered public health practitioners have no formal training in public health.<sup>8</sup> In fact, the Office of Workforce Planning and Policy at the CDC reports the following disturbing statistics.<sup>10</sup>

- Only 44% of the public health workforce has formal public health education.
- Only 22% of local public health officials have graduate degrees in public health.
- Only 40% of public health nurses-(the largest professional discipline in public health) have training in community based practice.

- Few public health workers have knowledge about the essential public health services and related competencies.

Efforts aimed at identifying, analyzing and enumerating the “public health workforce” has also been the subject of much debate and controversy over at least the past decade and many reports of these shortcomings in enumerating and categorizing the workforce have been generated.<sup>11, 12, 13</sup> The lack of any type of credentialing, certification, continuing education requirements or licensure is a major roadblock to enumerating those who are considered the public health workforce. In addition, public health provides a wide range of services in various employment settings including: clinics, federal, state, and local government. The functions, responsibilities, differing job titles and location of practice also influence appropriate enumeration and categorization. Several types of personnel categorized as public health workers can be captured due to other professional licensure requirements such as physicians, nurses, nutritionists, pharmacists, dental professionals, social workers and attorneys.

The last official comprehensive effort at enumerating the public health workforce was conducted in 2000 and 448,254 individuals were categorized as functioning in a public health capacity.<sup>11</sup> This represents one public health practitioner for every 635 people. (A decrease since the 1970’s in which the ratio was better- one public health practitioner for every 457 people). The public health workforce capacity has thus been eroding over time.

This is the best estimate of the size of the public health workforce, despite limitations such as over and undercounting certain job categories, and 25% of those counted not assigned to a specific worker type category.

Public health professionals consisted of 45% of the workforce and other public health workers accounted for 55%. In addition, there were 2,864,825 volunteers.

Of the 45% consisting of public health professionals:

- 25% public health nurses,
- 10% environmental professionals
- 7% public health laboratory worker
- 3% each; public health physician, public health nutritionist
- 1% each; public health educator, dental worker and social worker
- 0.5% epidemiologists
- 49% "all other professionals" (those that could not be identified by title or other titles)

Of the 55% consisting of public health workers:

- 12% administrative support
- 9% technicians
- 4% each; paraprofessionals, officials, administrators
- 1% service/maintenance
- 0.3% each; skilled craft, protective service
- 25% unreported category

Along with the problems in enumerating the overall public health workforce, two surveys of state public health agencies were conducted in 2002 and 2003 by the Association of State and Territorial Health Officials (ASTHO), Council of State Governments (CST) and the National Association of State Personnel Executives (NASPE).<sup>14</sup> The ensuing report predicted a looming shortage of public health employees in the coming years. Key findings included:

- A rapidly aging workforce whose average age is 46.6 years
- Public health retirement rates as high as 45% over the next 5 years
- Current vacancy rates of up to 20% in some states
- Public health employment turnover rates of 14% in some parts of the country.

Nurses, laboratory professionals, epidemiologists and environmental health specialists are the disciplines in which a shortfall in number of workers is projected. Of the thirty seven states that formed the basis for the survey, two of the most frequently cited strategies for retaining the current workforce included educational opportunities and higher pay and benefits.

Who will conduct the genomic training needed by the public health workforce? The clinical specialty with training in both genetics, counseling and family health are genetic counselors. However, there are only 1933 board certified genetic counselors, those uniquely equipped to provide key training to public health, and only 120-130 students graduate each year from the 26 genetic counseling programs.<sup>15, 16</sup> Today, there is only one genetic counselor for every 200,000 people.<sup>17</sup> Both matriculated students of public health in the academic community and the 500,000 public health practitioners and workers need training. With so few genetic counselors and so many in public health practice, the internet, a rich source of information in genomics, may serve as a bridge between trainers and trainees but learned intermediaries are needed to develop curricula and training programs.

#### **Public Health Functions and Services**

**Table 1** briefly describes the three core functions and the ten essential services of public health.<sup>12,18</sup> The ten essential services were originally developed through consensus from a group of public health organizations through the Public Health

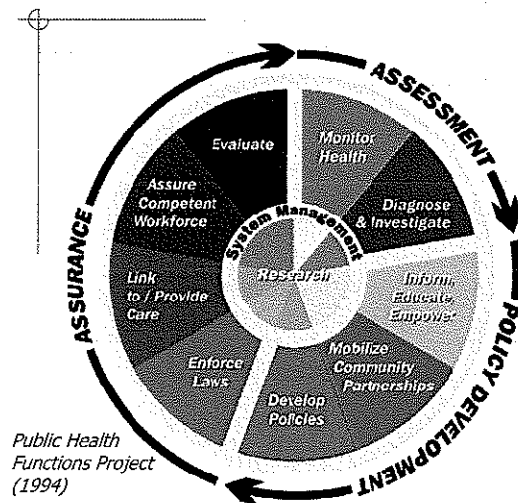
Functions Steering Committee in 1994. A visual depiction is provided in **Figure 2** within a genetics framework.

**Table 1. Three Core Functions & Ten Essential Services of Public Health**

Assessment	Policy Development	Assurance
1. Monitor health status to identify community health problems	3. Inform, educate, and empower people about health issues.	6. Enforce laws and regulations that protect health and ensure safety.
2. Diagnose and investigate health problems and health hazards in the community	4. Mobilize community partnerships to identify and solve health problems	7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable.
	5. Develop policies and plans that support individual and community health efforts.	8. Assure a competent public health and personal health care workforce.
		9. Evaluate effectiveness, accessibility and quality of personal and population-based health services.
<b>Serving All Functions:</b> 10. Research for new insights and innovative solutions to health problems.		

**Figure 2. The Integration of Genetics into Public Health: A Blueprint<sup>19</sup>**

## The Integration of Genetics into Public Health: A Blueprint



- ◆ *The Future of Public Health (IOM)*
- ◆ Tool to promote dialog, assist integration, and inform others

The majority of the essential services called for by the public health community can be linked to a potential genomic application. For example:

- **Essential Service #3-** Consumer education in genetics/genomics will be required to adequately inform the community as a result of media attention to genomics and the influence of genes/environment/behavior for focused prevention interventions and to promote health literacy among communities.
- **Essential Service #4-** Partnerships can be sought with genetic counselors and other health professionals with genetics training to help apply appropriate prevention strategies.
- **Essential Service #5-** Elevate the influence of genetics and behavioral/environmental influences to policymakers that illustrate how disease can potentially be mitigated by effective prevention strategies.
- **Essential Service #6-** Public health input on policy initiatives will need to be addressed to effect legislation relating to privacy, insurance, discrimination, legal, social and ethical issues that genomic technology has spawned.
- **Essential Service #7-** Knowledge of genetic professionals in the area, and where they are located so that appropriate and timely referrals may take place.



- **Essential Service # 8-** Training in genomics as a step towards assuring integration of new scientific advances into public health practice.
- **Essential Service #9-** The use of genetic testing for predisposition testing, carrier screening, requires oversight and adherence to standards of accuracy, analytic and clinical validity, utility, reliability and ethical, legal and social issues relating to such testing. Counseling will need to be provided to recipients of genetic tests for impact, meaning and appropriate context, especially with the advent of direct-to-consumer advertising of genetic tests over the internet.
- **Essential Service #10-** Health problems can be traced back to genetic susceptibility and certainly new research in genomics can be applied to the top ten causes of death.

Although many of the essential services can be linked to a genomics perspective, the focus will be on the Assurance Function, and particularly essential service #8. Without a public health workforce adequately trained in genomics, few of the other potential applications will be realized. Of note, is that two schools of public health in the United States have taken a leadership role in the development of formalized curricula within existing public health programs to address the emerging field of public health genetics- the University of Washington and the University of Michigan.<sup>20</sup> University of Pittsburgh has a longstanding program in

human genetics and genetic counseling available through the school of public health.

### **Top Ten Causes of Death in the United States**

Public health has long been concerned with mortality rates, disease risk and most notably those potentially preventable causes of death and disability (**Table 2**).

Many of the top ten causes of death in the United States, are potentially preventable because their acquisition is influenced by behavioral, lifestyle and environmental factors (smoking, nutrition, obesity, physical inactivity). While genetic variation also plays a role, it is not deterministic but rather contributes to the overall risk and timing of disease acquisition. One of the emerging roles of public health, therefore, is to embrace and understand the influence of genetic variation on disease risk, morbidity and mortality.

**Table 2. Top Ten Causes of Death in the United States 2003<sup>21\*</sup>**

<b>Cause of Death</b>	<b>Death Rate (per 100,000 population)</b>	<b>Number of Deaths (Absolute numbers)</b>
Diseases of the heart	235.4	684,462
Malignant neoplasms	190.7	554,643
Cerebrovascular disease	54.3	157,803
Chronic lower respiratory diseases	43.4	126,128
Accidents (Unintentional injuries)	36.3	105,695
Diabetes mellitus	25.4	73,695
Influenza and pneumonia	22.3	64,847
Alzheimer's disease	21.8	63,343
Nephritis/nephritic syndrome & nephrosis.	14.6	42,536
Septicemia	11.8	34,243
* Preliminary data for 2003-based on 93% of death certificates.		

### **Schools of Public Health-Directive and Actions**

Schools of public health have been given the national directive that eight new “critical” areas should be addressed in educating public health professionals. These areas include medical informatics, genomics, communication, cultural competence; community based participatory research, global health, policy and law, and public health ethics.<sup>8</sup> A survey of schools of public health published in October, 2004 revealed that although many schools of public health are making strides towards including content areas recommended by the IOM, genomics remains one of four areas that still require increased attention to content.<sup>22</sup> Of the percentage of schools offering core content in particular areas, the lowest was genomics at 15%. The authors did note that with the continuing advances in both genomics and information technology, these two areas are “likely to have a profound effect on public health practice and the health delivery system at large.”<sup>22</sup>

### **Public Health Funding**

For fiscal year 2006, the President’s budget proposal for the Department of Health and Human Services (DHHS) and its associated agencies is \$642 billion representing an increase of \$58 billion compared to 2005.<sup>23</sup> However, a number of funding cuts to particular agencies have been quite marked. Budget cuts have occurred in Health Resources Service Administration (HRSA) CDC, substance abuse and mental health services. The CDC, the premiere public health arm of the federal government, has a proposed budget of \$7.5 billion which represents a net decrease of \$491 million below 2005 funding levels. Of this, \$60 million has been

cut from the chronic disease prevention and health promotion program, another \$60 million cut in public health improvement and leadership and an additional \$60 million cut from public health research. In addition the internal structure of the CDC had undergone major changes (The Future's Initiative)<sup>24</sup> and is reorganizing the majority of its programs under four coordinating centers and three coordinating offices. This includes Infectious Diseases, Health Promotion, Public Health and Information Services, Environmental Health and Injury, Terrorism, Global Health and Workforce and Career Development. A lifestage approach is one key strategy with five categories of lifestages from newborn to elderly, each with measurable objectives and performance indicators for health protection.<sup>24</sup> It is not known where the Office of Genomics and Disease Prevention will fall under the new structure and budget reallocation.

### **Health Policy Issues**

Four key issue areas in genomics have been identified that are of “universal importance” to health policy and society including: genetic privacy, regulation and standardization of genetic tests gene patenting and education.<sup>25</sup> The role of local departments of public health cannot be overstated in conducting educational outreach efforts in the community for a variety of health issues including genomics. However, first public health practitioners must be trained. Barriers to incorporating genetic services among health care/public health practitioners include lack of knowledge, lack of referral guidelines, lack of clinical utility, lack of updated or detailed family history, competing time demands, fear of unanticipated consequences of genetic testing among others.<sup>26, 27, 28</sup> However,

one of the oldest applications of genetics is in newborn screening for genetic disorders for which public health has been the leading champion. Collection of family history is also a function most health providers perform though quality of the collection varies; this too is considered “genetics.” The Surgeon General,<sup>29</sup> along with other health organizations such as NCHPEG,<sup>30</sup> AMA,<sup>31</sup> AAFP,<sup>32</sup> CDC<sup>33</sup> and NSGC<sup>34</sup> have been promoting health care provider education in collecting accurate family medical histories.

### **The Genomic Information Explosion**

The genomic resources available on the internet have grown exponentially in recent years and can truly be considered an explosion. Searches of the internet using two popular search engines (Google and Yahoo) were performed to identify the quantity of information. In addition, a search of the medical literature from the National Library of Medicine (PubMed) was conducted using a keyword search strategy. The keywords included were: gene, genetics, genomics, pharmacogenetics, pharmacogenomics and the phrase “genetics of disease.” Literally, millions of websites were identified representing the myriad of information both reliable and otherwise a health professional or consumer could locate using a general search engine or PubMed to locate these terms. Although approximately 63% of American adults have internet access, about one-third does not have access for a variety of reasons.<sup>35</sup> Many libraries, universities and other public institutions provide freely available workstations with internet access for those who wish to utilize these resources. **Tables 3 and 4** tabulates the findings

from two internet search engines and the medical literature related to keywords in genomics.

**Table 3. Internet Search Engine Retrievals by Keyword: March 5, 2005**

Terms	Search Engine/Date	# Hits
Gene	Google, 3/5/05	30,100,000
Gene	Yahoo, 3/5/05	35,100,000
Genetics	Google, 3/5/05	15,900,000
Genetics	Yahoo, 3/5/05	12,800,000
Genomics	Google, 3/5/05	4,740,000
Genomics	Yahoo, 3/5/05	2,169,000
Pharmacogenetics	Google, 3/5/05	262,000
Pharmacogenetics	Yahoo, 3/5/05	120,000
Pharmacogenomics	Google, 3/5/05	300,000
Pharmacogenomics	Yahoo, 3/5/05	198,000
Genetics of disease	Google, 3/5/05	4690
Genetics of disease	Yahoo, 3/5/05	1,280

**Table 4: Medical Literature Retrievals by Selected Term, March, 5, 2005**

Terms	Source/Date	# Hits
Gene	PubMed/3/5/05	761,098
Genetics	PubMed/3/5/05	1,359,120
Genomics	PubMed/3/5/05	9,849
Pharmacogenetics	PubMed/3/5/05	2,839
Pharmacogenomics	PubMed/3/5/05	2,711
Genetics of Disease	PubMed/3/5/05	155,194

### **The Internet and the Media**

The use of the internet has blossomed over the past decade. Originally developed for government defense use, it has permeated mainstream society with approximately 63% of US adults (128 million) and 81% of teenagers as regular users.<sup>35</sup> The Pew Internet & American Life Project (PIP) funded by the Pew Charitable Trusts conducts ongoing surveys of uses of the internet by the public. Approximately 94 million Americans have used the internet for health or medical purposes. Of those that go online, 85% women seek health information vs. 75% of men. Based on age, of those online, 70% of middle age users (ages 30-64)

seek health and medical information vs. 57% of younger and older internet users.<sup>35</sup> In a 2002 survey, 38% of internet users say the internet has improved the way they take care of their health.<sup>35</sup> Of 100 million internet users belonging to an online “community,” 28% belong to a support group for a medical condition or personal health problem.

Of the close to 94 million Americans using the internet for health-related matters, the majority look for information about a specific disease or condition. **Table 5** outlines the types of information online health seekers access.<sup>35</sup>

**Table 5. Type of Information Sought by Online Health Seekers<sup>35</sup>**

Type of Information	Percent of Users
Specific disease	63%
Treatments/Procedures	47%
Diet/Nutrition	44%
Exercise/Fitness	36%
Medicines	34%
Alternative medicines	28%
Health insurance	25%
Mental illness	21%
Particular physicians/hospitals	21%
Experimental Treatments	18%
Environmental health hazards	17%
Vaccinations	13%
Sexual health	10%
Medicare/Medicaid	9%
Substance Abuse	8%
Smoking cessation	6%

Derived from Pew Internet & American Life Project, December 2002, survey of 94 million Americans using the internet for health related matters.

Searching governmental websites is a regular practice of 97 million Americans of which 36 million have sought health and safety information.<sup>35</sup> Of interest is that consumers say their health use of the internet is important due to convenience, (93%), they get more health information than they do from other sources (83%),

and they can get the information anonymously (80%). Surveys report that people feel more in control of their own health care when actively seeking information. However, most just began searching on their own (86%) vs. asking for advice about relevant health websites from others (14%).<sup>36</sup>

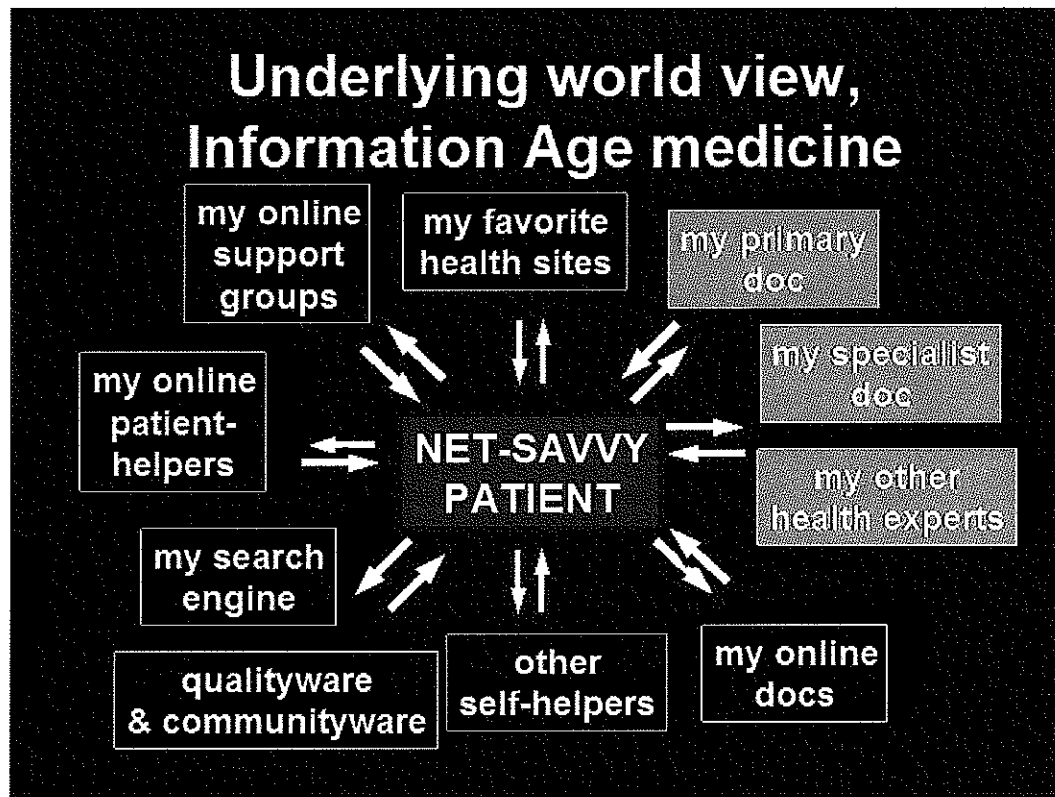
Once people locate information they are seeking, one in three bring it to a physician for verification and a quality check, two in five check the source and many health seekers reject sites that appear to have commercial messages.<sup>36</sup>

However, most people still get most of their health information from their physician. Consumers not only look for health information for themselves and others on the internet, but 73% who look for information for themselves say the material they locate affect decisions about treatments and care, whether to visit a physician and whether to ask questions and get a second opinion. Half say the information influenced their nutrition and exercise habits.<sup>36</sup> The report also found that 11 million Americans who helped a loved one deal with an illness in the past two years said their use of the internet played a crucial or important role in their helping others and more than 4 million said the internet helped them cope with their own major illness.<sup>36</sup>

The transition to information age healthcare with various inputs into patient decision making has begun according to Lee Rainie, investigator in the Pew Internet & American Life Project and is depicted in **Figure 3**.



**Figure 3. Information Age Medicine**



(Source: Rainie, L. Pew Internet & American Life Project. Presented at Internet Librarian Conference November 3, 2003, Monterey, CA)

The popular media is also a source to raise issues related to genetics and genomics. Popular movies such as Gattica, The Island of Dr. Moreau, Jurassic Park, Blade Runner, Lorenzo's Oil are a few examples of popular films that depict genetics in a deterministic and invariably evil way. Other sources of perspective and information include newspaper articles, radio talk shows and magazines for the public such as Scientific American and Time have covered genetic-related issues over the past several years. Time magazine has sported several thought-provoking articles related to the ethical, legal, social and scientific issues of genomics. Selected examples of Time magazine covers are included in **Appendix 3.**

Quality health information is available, but so too lurks misinformation and commercialism. The public health community will surely be approached by consumers and patients with questions about various genetic issues relating to disease, genetic tests advertised over the internet and other issues relating to media headlines about health, illness and disease genes. Patients have already approached their personal physicians with information found on the internet. Thus, the use of the internet as a resource for genomics education may provide a cost-effective means for educating the public health workforce.

### **Competency Based Training**

A competency is defined as the knowledge, skills and abilities necessary to achieve a standard level of worker performance. Competencies are actions which are observable in the execution of ones work in the application of skills and knowledge.<sup>37</sup>

The January 2000 Strategic Plan for Public Health Workforce Development calls for all workforce development efforts to be competency-based and facilitated by ready access to life-long learning.<sup>38</sup> However, surveys of various healthcare professionals have generally revealed that confidence in genetics knowledge is low and additional training is desirable. Lapham et al. conducted a random sample mail survey of 6 health professional organizations as part of the human genome education model (HuGEM) initiative.<sup>39</sup> An overall response rate of 57% was obtained from 3600 health professionals (approximately 600 from each association). The groups surveyed included: American Dietetic Association, American Occupational Therapy Association, American Physical Therapy Association, American Psychological Association, American Speech-Language-Hearing Association and the National Association of Social Workers. Almost two-thirds of those surveyed said they would be interested in attending continuing education workshops in genetics at their conferences. Over one-third of those surveyed were interested in receiving training to provide education on genetic issues to colleagues, patients and students. The topics of most interest included: role of genetics in common diseases such as stroke, heart disease and cancers, overview of human genetics, identifying genetic resources for clients, helping clients cope with a new genetic diagnosis, genetic information and racial/ethnic concerns, new treatments for genetic disorders including gene therapy, privacy and confidentiality issues in releasing genetic information to others such as health insurers, schools and employers, and communicating genetic information to clients.

A comprehensive document has been developed to aid in developing curricula for the public health workforce from sets of competencies. The document, entitled Competency-to-Curriculum Toolkit: Developing Curricula for Public Health Workers was a collaborative effort from many organizations and developed by the Center for Health Policy at Columbia University School of Nursing and the Association of Teachers of Preventive Medicine.<sup>37</sup>

### **Conclusion**

The convergence of a number of related factors has opened a window of opportunity for assuring the public health workforce has the necessary genomics background and competencies needed to maintain effectiveness in the 21<sup>st</sup> century. Opportunities for lifelong learning abound, if public health leadership is committed to adequately and appropriately preparing and training the workforce to operate in an environment experiencing rapid change, ongoing discovery and cutting edge science.

The Genomic Competencies/Resource Project referred to herein combined with guidance from the Competency-to-Curriculum Toolkit may serve as the basis for health educators, curriculum developers and others with a role in public health workforce development to begin converting the competencies and resources into curricula and training programs in genomics for the public health workforce.

### **Existing Genomic Competencies**

**Table 6** represents a compilation of competencies, policies, position statements, and curricula as related to genetics/genomics for health professionals. University of Washington and University of Michigan have specific curricula in public

health genetics. Two key competency sets; one from the National Coalition for Health Professional Education in Genetics (NCHPEG) and the Centers for Disease Control and Prevention (CDC) are the most comprehensive and developed with dialogue among a broad cross section of stakeholders.

NCHPEG is a consortium of 120 member organizations including health professional organizations, consumer and voluntary groups, government agencies, private industry, managed care organizations and professional genetics societies. The group was established in 1996 by the American Medical Association, the American Nurses Association and the National Human Genome Research Institute in order to promote health professional education and access to information about advances in human genetics. A set of core competencies in genetics relevant to all health professionals including medicine, nursing, allied health, public health, pharmacy, dentistry, psychology, social work and others was developed by a taskforce of NCHPEG members and made available on their website in 2001 (**Table 6**). These competencies represent the minimum knowledge, skills and attitudes necessary to incorporate an awareness of genetics in patient care. A detailed history of the process involved in the development of the NCHPEG core competencies was published in 2001.<sup>40</sup>

CDC convened working groups to develop competencies in genomics specific for the public health workforce in 2000.<sup>41</sup> The intention was to incorporate genomics into the framework of the three core functions and ten essential services of public health (**Table 1, Figure 2**). The working groups were composed of fifty state and

local public health officials, as well as representatives from the academic and private sector spanning multiple specialties. The competencies thus developed were intended to provide the basis for planning, prioritizing and developing curricula and training to shape formal educational programs and ongoing training projects in addition to the development of performance standards.

The competencies have been categorized by job function and include all public health workforce, all public health professionals, clinicians, epidemiologists, laboratorians, environmental health professionals, leaders/administrators and health educators. These competencies were also made available in 2001 at the CDC website (**Table 6**).

**Table 6. Existing Competency Sets in Genomics**

CDC <sup>42</sup>	<b>Centers for Disease Control and Prevention</b> Competencies for public health professionals (included are subsets of competencies for all public health workforce, all public health professionals, laboratorians, clinicians, environmental health personnel, leaders/administrators, epidemiologists, and health educators). <a href="http://www.cdc.gov/genomics/training/competencies/comps.htm">http://www.cdc.gov/genomics/training/competencies/comps.htm</a>
NCHPEG <sup>43</sup>	<b>National Coalition for Health Professional Education in Genetics</b> Genomic competencies for all health professionals <a href="http://www.nchpeg.org/nchpeg.html?http://www.nchpeg.org/eduresources/core/core.asp">http://www.nchpeg.org/nchpeg.html?http://www.nchpeg.org/eduresources/core/core.asp</a> (Also available in Spanish).
AAFP <sup>44</sup>	<b>American Academy of Family Physicians</b> Competencies for Family Practice Physicians <a href="http://www.aafp.org/x16547.xml">http://www.aafp.org/x16547.xml</a>
ASHG <sup>45</sup>	<b>American Society of Human Genetics</b> Policy guideline-Competencies For Physicians <a href="http://genetics.faseb.org/genetics/ashg/policy/rep-01.htm">http://genetics.faseb.org/genetics/ashg/policy/rep-01.htm</a>
ASTHO <sup>46</sup>	<b>Association of State and Territorial Health Officials</b> Policy guideline-Public Health Genetics <a href="http://www.astho.org/pubs/consolidatedpolicy.html#PHG-1_PubHealthGenetics">http://www.astho.org/pubs/consolidatedpolicy.html#PHG-1_PubHealthGenetics</a>

ASTCDD <sup>47</sup>	<b>Association of State and Territorial Chronic Disease Directors</b> Working Group Report <a href="http://www.chronicdisease.org/Genomics_Summit_Report.pdf">http://www.chronicdisease.org/Genomics_Summit_Report.pdf</a>
UMI SPH <sup>48</sup>	<b>University of Michigan, School of Public Health</b> Educational program in public health genetics. <a href="http://www.sph.umich.edu/geneticsed/">http://www.sph.umich.edu/geneticsed/</a>
UWA SPH <sup>49</sup>	<b>University of Washington, School of Public Health</b> Public Health Genetics degree/core courses/curriculum <a href="http://depts.washington.edu/phgen/DegreeTracks/phd.html">http://depts.washington.edu/phgen/DegreeTracks/phd.html</a> <a href="http://depts.washington.edu/phgen/DegreeTracks/competencies.html">http://depts.washington.edu/phgen/DegreeTracks/competencies.html</a> <a href="http://depts.washington.edu/phgen/Curriculum/CoreCourses/PHG.html">http://depts.washington.edu/phgen/Curriculum/CoreCourses/PHG.html</a>
UPitt, SPH <sup>50</sup>	<b>University of Pittsburgh School of Public Health</b> <a href="http://www.hgen.pitt.edu/academics/mph.html">http://www.hgen.pitt.edu/academics/mph.html</a> <a href="http://www.hgen.pitt.edu/academics/index.php">http://www.hgen.pitt.edu/academics/index.php</a>
ABGC <sup>51</sup>	<b>American Board of Genetic Counseling</b> <a href="http://www.abgc.net/genetics/abgc/accred/acc-03/2004_Required_AC_Criteria.pdf">http://www.abgc.net/genetics/abgc/accred/acc-03/2004_Required_AC_Criteria.pdf</a>

## The Genomics Competency/Resource Project

**Description:** *The Genomics Competency/Resource Project* was conceived and undertaken as a practicum initiative in January 2004. A practicum is a required component of the curriculum at the University of North Carolina, School of Public Health for the masters of public health (MPH) degree. The practicum was conducted under the auspices of the North Carolina Center for Genomics and Public Health (NCCGPH), one of three nationwide centers funded over a 3-year period through mid 2005 by the Centers for Disease Control and Prevention (CDC). The mission of the NCCGPH is to prepare the public health workforce to respond to advances in genetic technology and to incorporate genomics into the everyday language and practice of public health. Objectives include knowledge base development, technical assistance and training.<sup>52</sup>

**Impetus:** The impetus for the project revolved around the recognition that genomic competencies existed in one world (paper/publications) and genomic educational and resource materials existed in another (world of the web). The overarching goal and source of excitement in undertaking this project was to serve as an intermediary for merging and customizing the genomic competencies with reliable sources of information and resources freely available on the internet.

**Objective:** The primary objective of *The Genomics Competency/Resource Project* was to address essential public health service #8: “Assure a competent public health and personal health care workforce” in the area of genomics. The competencies, objectives and resources provided herein can be used as a tool to provide health educators and public health faculty with resources to help guide curriculum development in genomics. The content component of the project with competencies and resources will be shared with the University of North Carolina, School of Public Health and the North Carolina Task Force on Genomics and Public Health. The Task Force was developed in the Office of Genomics under the Chronic Disease and Injury Section of the Division of Public Health in the North Carolina Department of Health and Human Services (NCDHHS). The mission of the office of genomics is to ensure that North Carolina monitors new genomic knowledge in terms of science, technology, ethics, law and policy. The task force was convened in order to ensure the benefit of genomic advances for all North Carolina citizens and to monitor discoveries in genomics and help to channel them into more effective disease detection, prevention and treatment initiatives that will improve public health. The content will be adapted for



inclusion in a subsection of the state of North Carolina website (Genomics and Public Health Task Force) which is currently in the developmental phases.

**Target Audience:** The target audience for the competencies and resources include public health practitioners with limited background and no formal training in genetics/genomics. Many of the website links contain information for a variety of professional medical audiences. Some sites are geared towards public health practitioners, others to certain categories of health care providers and clinicians in general and others towards patients. All websites have been reviewed and represent sources of learning and competency development for a broad healthcare provider audience.

**Process: Review of Existing Genomic Competencies and Selection/Revision**

Genomic competency sets (**Table 6**) were identified utilizing several methods including use of a literature search using PUBMED (a freely accessible search engine that covers the medical literature). In addition, internet searches were conducted using: Google and Yahoo, two popular internet search engines. Terms and phrases for the search included genetics, genomics, competencies, education, health professional education, public health, public health education, public health workforce development and health professional in a variety of combinations. Various organizations and university websites were also perused individually for genomic competencies. After reviewing the medical literature, numerous governmental, university and professional websites, 10 major sets of competencies were identified as relevant to genomics education for public health practitioners (**Table 6**).

The genomic competencies and related materials such as policy and position statements and curriculum descriptions were analyzed for similarities and differences according to depth, audience, scope and degree of detail. The most notable differences included the specific wording of the competencies and depth of knowledge which appeared to depend upon the intended audience and source (university course/degree track, vs. public health practitioners vs. all healthcare practitioners).

After reviewing the existing competency sets in detail, ten, genomic “topics” were identified as most relevant to initial training endeavors for the public health workforce. These competencies were ranked from # 1-#10 based on what appeared to be a natural learning progression. The CDC and NCHPEG competencies contained the most overlap and formed the key elements for competency topic selection.

Specific learning objectives were developed to coincide with each competency topic based on relevance to a broad group of public health practitioners, practicality, and applicability to various public health services. The competency topics and objectives were subsequently reviewed by a core group of three experts: A Ph.D.-trained epidemiologist with a masters of science in public health (MSPH), a board-certified genetic counselor with a masters of science (MS) in human genetics, and a registered pharmacist (R.Ph.), with a Bachelor of Science (BS) in pharmacy, experience in health communications and pursuing a doctoral degree in public health. The trio made some suggested revisions and deemed

these competencies/objectives to be a reasonable starting point for education in genomics for a self-starting public health practitioner, health educator, or faculty member to use in the development of appropriate training materials and curricula.

### **Review and Selection Process for Internet Resources**

Research was conducted via the web for relevant and appropriate genomic resources. Each search engine hit led to numerous other sites with deeper knowledge, more individual resources, and even more lists of resources. The amount of high quality information that was freely available was overwhelming. Hundreds of sites were evaluated, and a selection process ensued based on the focus of the site, meeting the objectives for the specified competencies, relevance and reliability of information, free availability and appeal to a general audience of public health practitioners. Criteria for reliable medical information on the web were used in assessing the sites. All of the web resources represent reliable sources of information from government agencies, academia, health departments, professional societies, hospitals and industry. Many sites have the HONcode symbol on their website for Health Information on the Net (HON). The HONcode subscribes to 8 ethical principles/criteria for quality web-based information. These criteria include: authority of the information provided, data confidentiality and privacy, proper attribution of sources, transparency of financial sponsorship and the importance of clearly separating advertising from editorial content. The HONcode seal of approval is given to websites who meet all eight criteria and approximately 3600 websites currently have the seal of approval.<sup>53</sup> Health information can be searched through HON directly, or a

symbol will appear on a website if the web-developer has subscribed to the code of conduct and applied for the seal of approval.

**Figure 4. Health on the Net Code (HONCode)**



The National Library of Medicine (NLM) has an online document entitled: MedLine Plus Guide to Healthy Web Surfing.<sup>54</sup> This document is intended to provide guidance to consumers on how to evaluate medical information on the internet. In addition, the NLM also contains links to a variety of other resources that provide information on how to evaluate health information.<sup>55</sup>

The National Coalition for Health Professional Education in Genetics (NCHPEG) launched a website in 2004 called GROW (Genetics Resources on the Web).<sup>56</sup>

The mission of GROW is to “optimize the use of the web to provide health professionals and the public with high quality information related to human genetics, with a particular focus on genetic medicine and health.” Each genetic site is evaluated and must meet strict criteria to be listed. This resource was developed due to the volume of genetic related websites with questionable information. Basic and advanced search capabilities allow the user to search for topics in a particular area of interest.

**Multiple competency areas**

Many of the links contain information which address several competency areas. In those cases, links were placed with the competency which appeared to be the

focus of the information in the website. Every effort was made to link directly to the specific site of interest.

### **Requirements for viewing some content on the websites**

Requirements for viewing some of the websites or portions of sites may require various plug-ins and computer capabilities for streaming video and audio.

Macromedia FlashPlayer, Shockwave, Real-Player, MP3, PowerPoint, Adobe Acrobat Reader or other programs may be required to view some of the sites, however, most are available for free download from the specific sites that use these plug ins.

As of March 27, 2005, all of the websites referred to herein were accessed and in working order. Due to the dynamic nature of the internet, some sites may have undergone revisions, updates or other changes that may make them inaccessible at times. Each website is a direct link to the relevant learning materials rather than a general homepage.

### **Cultural competence**

Multilingual materials are available on many of the websites to address the information needs of practitioners and their clients who are multilingual. The sites with information in other languages have been denoted as such. Many materials are available in Spanish and some have also been translated into other languages. Some direct links may not be available in multiple languages, but the source homepage may have links to relevant multilingual educational materials. In addition, some sites provide a translation functionality in which all of the materials on the site can be translated into different languages.

### **Linking to Websites**

Linking to particular websites may require permission from the administrator of the homepage on specific sites. Most governmental websites do not have specific link-related requirements but may require that appropriate credits be provided in a particular way when linking to their site. Some sites may also have copyright instructions/restrictions for copying, printing, reproducing and distributing materials found on their site. Some of the materials may be subject to different rules which may be applicable to selected uses of the information such as educational or commercial uses. Any necessary permissions and copyright fees required should be determined prior to using the materials.

### **Availability**

The majority of websites cited for competency development are available free of charge, however, some may require a one time (free) user registration. Some sites have been listed which are links to training programs and courses which may charge a fee to obtain continuing education credits associated with their programs. Those sites which may require a fee for accessing certain materials or portions of their sites or for CE credit are marked with a dollar sign (\$) where relevant.

### **Websites not included**

Over the course of a year, internet searches were conducted to locate reliable and relevant sources of electronically available information on genomics specifically suited to public health practitioners. Many of the sites visited had a plethora of information and additional links, resources, games, teacher training materials,

case studies and specific disease information on many hundreds of disorders. Because of the overwhelming nature of information related to genomics content on the web, distillation was a necessary process in order to focus on the competency areas with a reasonable number of websites. The non-inclusion of any particular website does not necessarily imply non-endorsement. It is clear from **Table 3** that millions of websites exist of which only a small fraction was selected. Many other high quality websites exist, however, due to sheer volume, they were not included here.

## **Competency 1: Background and History of Genetics**

*The participant should be able to:*

- *Explain the major historical milestones and timeline of genetic discoveries contributing to the current understanding of genetics/genomics.*
- *Develop a basic understanding of the history of genetics research including the role of key scientists and their contributions: from Gregor Mendel with his experiments with peas in the mid 1800s to the present with Francis Collins and Craig Venter announcing the completion of the map of the human genome.*
- *Understand the history and role of the Human Genome Project (HGP).*
- *Describe the Eugenics movement and its implications for genetic/genomic research.*

## ***Milestones/Timelines/Key Scientists***

From Cold Spring Harbor Laboratory (CSHL) and Dolan DNA Learning Center (DDNALC) (funded by HHMI) *DNA Interactive (DNAi)* An interactive history of the discovery of DNA and modern genetics. A great *Timeline of Genetic Discoveries* with many key scientists interviewed (audio/video-clips and pop-up biographical sketches) mentioned in the process of discovery of DNA. Visit each decade from the pre-1920s to the present and see a parallel timeline of the events going on in the rest of the world at the same time.<sup>57</sup>  
<http://www.dnai.org/timeline/index.html>

From National Institutes of Health (NIH), an online exhibit from the Museum of Medical Research entitled: *Deciphering the Genetic Code*, explores the history of genetics research in the 1950's and 1960's and the importance of the work done by Marshall Nirenberg who won the Nobel Prize in 1968 for "breaking the genetic code." Contains biographies of many scientists instrumental in solving the mysteries of the genetic code.<sup>58</sup>  
<http://history.nih.gov/exhibits/nirenberg/index.htm>

From Discovery Channel, Discovery Health. A historical summary of genetics entitled: *The History of Modern Genetics* Describes the age of Gregor Mendel to the modern era of genetics to the age of genomics, to human genetics.<sup>59</sup>  
[http://health.discovery.com/minisites/dna/\\_zw\\_history.html](http://health.discovery.com/minisites/dna/_zw_history.html)  
(Notes: includes a section with suggested readings; some of which have full text links).

## **Human Genome Project/Activities**

From the National Human Genome Research Institute (NHGRI): Several webcasts, learning resources and activities from the first *National DNA Day* in April, 2003. Includes a placeholder for celebrating the upcoming anniversary of DNA day on April 25, 2005.<sup>60</sup>  
<http://www.genome.gov/10506367>

From the Kaiser Network Health-casts: A web-cast conducted April 2003 entitled: *Bringing the Genome to You: Human Genome Project to Society*.<sup>61</sup>  
[www.kaisernetwork.org/healthcast/nhgri/15apr2003/](http://www.kaisernetwork.org/healthcast/nhgri/15apr2003/)  
(Notes: requires RealPlayer).

From the National Human Genome Research Institute (NHGRI): 50 years of DNA: from double helix to health. A variety of links to webcasts, educational materials and curricula concerning the human genome. Activities conducted in April 2003.<sup>62</sup>  
<http://www.genome.gov/10005139>



From the US Department of Energy (DOE) and the Human Genome Project (HGP): An online guide entitled: *Genomics and its Impact on Science and Society: The Human Genome Project and Beyond, A 2003 Primer*. This primer covers basic genetics, the Human Genome Project, ELSI, medicine and the new genetics, benefits of genetic research, future scientific challenges, and more.<sup>63</sup>  
[http://www.ornl.gov/sci/techresources/Human\\_Genome/publicat/primer2001/index.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/publicat/primer2001/index.shtml)

(Notes: Available in html, adobe. Requires powerpoint for slide viewing and adobe acrobat reader if you choose to view PDF. PowerPoint slides accompany the primer).

## **Eugenics**

From the Dolan DNA Learning Center (DDNALC), Cold Spring Harbor Laboratories. *Eugenics – Image Archive on the American Eugenics Movement*. This is a library of images and information from the eugenics era and contains a searchable database of images and information.<sup>64</sup>  
<http://www.eugenicsarchive.org/eugenics/>

## **Competency 2: Genetics/Genomics Terminology**

*The participant should be able to:*

- *Understand the basic language of genetics/genomics by becoming familiar with the most common genetic terminology/vocabulary, abbreviations and pronunciation as related to general terms, terms related to chromosomal structure and function, clinical and medical genetics, laboratory testing, and the biotechnology industry.*
- *Acquire the ability to briefly define and correctly pronounce genomics related terms, explain a term or abbreviation to a patient in layman's language or to another healthcare provider.*
- *Continually update knowledge and familiarity with terms related to genomics and to locate and navigate*

*resources for identifying new terms related to genetics and genomics.*

- *Identify the difference between genetics and genomics.*

From the National Human Genome Research Institute (NHGRI): This is a “talking” glossary of genetic terms which includes phonetic spellings and audio clips for correct pronunciation.<sup>65</sup>

<http://www.genome.gov/10002096> (English version)

<http://www.genome.gov/sglossary.cfm> (Spanish version)

(Notes: includes a search function, multilingual, requires RealPlayer).

From the Human Genome Project (HGP): A glossary of genetic terms in an A-Z index. You can also browse the whole glossary. There is a wealth of information other than the glossary.<sup>66</sup>

[http://www.ornl.gov/sci/techresources/Human\\_Genome/glossary/](http://www.ornl.gov/sci/techresources/Human_Genome/glossary/)

From the Genetics Home Reference (GHR): a service of the U.S. National Library of Medicine (NLM). This site is an A-Z glossary of genetics terms of which you can browse the whole glossary or select a specific term.<sup>67</sup>

<http://ghr.nlm.nih.gov/ghr/glossary/Glossary.jsessionid=FD02D1BEFA70709B6D9E24B04996C6F7>

From GeneTests funded by National Institutes of Health (NIH): An illustrated glossary of genetic/genomics terms with definitions, descriptions, illustrations and case examples.<sup>68</sup>

<http://www.genetests.org/servlet/access?qry=ALLTERMS&db=genestar&fcn=term&gtreport2=true&id=17563&key=i3UZrab5qemYo>

From Access Excellence at the National Health Museum funded by Department of Health and Human Services (DHHS)- Glossary of terms relating to the structure of DNA.<sup>69</sup>

[http://www.accessexcellence.org/AE/AEC/CC/DNA\\_glossary.html](http://www.accessexcellence.org/AE/AEC/CC/DNA_glossary.html)

From the Virtual Children’s Hospital at the University of Iowa-Glossary of genetic abbreviations.<sup>70</sup>

<http://www.vh.org/pediatric/provider/pediatrics/ClinicalGenetics/AppendixB/AppenBGlossofAbbrev.html>

### Competency 3: Ethical, Legal and Social Issues with Genomics (ELSI)

*The participant should be able to:*

- *Develop an understanding of the various issues and viewpoints that arise about ethical, legal and social issues surrounding genomics, including topics relating to disclosure of information on genetic risk and disease predisposition to family members, implications of an individual's own genetic test results on family members, medical privacy, insurance, employment and, discrimination.*
- *Develop an awareness of the policy issues and debate surrounding human cloning, stem cell collection and research, pre-implantation genetic diagnosis and embryo selection, genetic testing of minors and the implications of genetic testing in the workplace.*
- *Develop the ability to identify various uses of genomics including, data collection of genetic information for Bio-banks, use of stored specimens, legal rights regarding specimen handling and privacy, privacy of medical records including genetic diagnoses, informed consent process in clinical trials and issues of patient access to the benefits of genomic advances.*

From the National Human Genome Research Institute (NHGRI): *Policy and Legislation Database*: a searchable database of policy and legislative documents relating to privacy of genetic information/confidentiality; informed consent; insurance and employment discrimination; genetic testing and counseling; and commercialization and patenting.<sup>71</sup>

<http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm>

(Notes: Search by state, content, topic or source).

From the US Department of Energy (DOE), Human Genome Project (HGP) *Genetics and Patenting*: a brief introduction to commercialization and patenting of genes. Provides links to other government projects related to ELSI issues and publications of interest.<sup>72</sup>

[http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/patents.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/patents.shtml)

From North Carolina Center for Genomics and Public Health (NCCGPH) -A collaborative effort through the Universities of Washington, Michigan and North Carolina schools of public health. This is a video narrated by Wylie Burke of University of Washington, Seattle, entitled: *Policy Issues in Genetic Testing* from The Genomics Revolution and Public Health Series.<sup>73</sup>  
<http://www.sph.unc.edu/nccgph/phgenetics/video.htm>  
(Notes: requires RealPlayer and audio/video capabilities).

From Action Bioscience: A review entitled: *Primer on Ethics and Human Cloning*.<sup>74</sup>  
<http://www.actionbioscience.org/biotech/mcgee.html>

From the American Academy of Pediatrics (AAP), Section on Bioethics entitled: *Ethical Issues with Genetic Testing in Pediatrics*.<sup>75</sup>  
<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;107/6/1451.pdf>  
(Notes: requires adobe acrobat reader, PDF of article from Pediatrics June, 2001).

From the National Human Genome Research Institute (NHGRI): Summary from a Direct to Consumer Advertising Workshop (March 23, 2004) entitled: *Direct to Consumer Marketing of Genetic Tests*.<sup>76</sup> <http://www.genome.gov/12010659>  
(Notes: includes link to workshop held in March, 2004 and participant perspectives).

From the Centers for Disease Control and Prevention (CDC): A resource to links about ethical, legal and social issues in genetics from a variety of sources.<sup>77</sup>  
<http://www.cdc.gov/genomics/links/ethical.htm>

## **Competency 4: Population Genetics**

*The participant should be able to:*

- *Describe the newborn screening process and the tests that are performed on newborns and how they vary by state.*
- *Describe genetic predisposition to certain diseases and screening initiatives among various ethnic groups for certain genetic diseases.*
- *Develop an awareness of chronic disease epidemiology and the relative contributions of genetics, environment*

*and lifestyle factors on disease predisposition and acquisition.*

## **Newborn Screening**

From the Maternal and Child Health Bureau (MCHB) and Health Resources Service Administration (HRSA) - *Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children*. This committee has the task of evaluating and making recommendations for the most appropriate application of universal newborn screening tests, technologies, policies, guidelines and programs for effectively reducing morbidity and mortality in newborns and children having or at risk for heritable disorders. Links to presentations and minutes of advisory board meetings held between June 2004-April 2005.<sup>78</sup>  
<http://mchb.hrsa.gov/programs/genetics/committee/>

From the Public Health Program Planning Office (PHPPPO), Centers for Disease Control and Prevention (CDC) and the Public Health Training Network (PHTN). An online Webcast originally broadcast September 19, 2002, entitled: *A New Era in Newborn Screening: Saving Lives, Improving Outcomes*.<sup>79</sup>  
<http://www.phppo.cdc.gov/PHTN/webcast/newborn/default.asp>  
(Notes: includes case studies on MCADD, sickle cell disease, homocystinuria and phenylketonuria). Registration required for CE credit. Video available \$, Requires RealPlayer).

From the Genetic Science Learning Center (GSLC) at the University of Utah. A 54-page activity guide with illustrations entitled: *Newborn Genetic Screening, What Should We Test and Why?* An educational activity in which you play the role of a citizen task-force member with the remit of helping policymakers guide decision-making and recommendations for genetic testing for newborn infants. Information is provided about medical conditions, sample storage, costs, legislation and more.<sup>80</sup>  
<http://gslc.genetics.utah.edu/teachers/units/newborn/NGS-student%20packet.pdf>  
(Notes: requires adobe acrobat reader to view/download PDF file).

From the North Carolina State Laboratory for Public Health (NCSLPH): *Newborn Screening*- contains information on conditions tested, specimen collection, reporting, forms and publications.<sup>81</sup> <http://slph.state.nc.us/Newborn/default.asp>

From the March of Dimes (MOD): Educational module entitled: *Newborn Screening for Genetic Disorders*.<sup>82</sup> [http://marchofdimes.com/pnhec/298\\_834.asp](http://marchofdimes.com/pnhec/298_834.asp)

From the National Newborn Screening and Genetic Resource Center (NNSGRC) Genetic and Newborn Screening Resource Center of the United States. (GeNeS-

R-US) A site with many links to sites with information on newborn genetic and screening issues.<sup>83</sup>

<http://genes-r-us.uthscsa.edu/index.htm>

From the Mountain States Genetics Network (MoStGeNe): *Newborn Screening Practitioners Manual* (October, 2003). Designed to assist practitioners in understanding the components of newborn screening and their importance in ensuring that children affected with these conditions are able to achieve their highest potential. Much of the resource information refers to the mountain states region.<sup>84</sup>

<http://www.mostgene.org/pract/praclist.htm>

From the Virtual Children's Hospital at the University of Iowa, *A Glossary of Malformations*. (authors from University of South Dakota).<sup>85</sup>

<http://www.vh.org/pediatric/provider/pediatrics/ClinicalGenetics/AppendixB/AppendixBGlossMalf.html>

From the National Conference of State Legislators (NCSL) *Genetics Technology Project- Newborn Genetic and Metabolic Screening*. A variety of resources and links to newborn screening issues.<sup>86</sup>

<http://www.ncsl.org/programs/health/genetics/nbs.htm>

From the Centers for Disease Control and Prevention (CDC), Morbidity Mortality Weekly Reports (MMWR): *Newborn Screening for Cystic Fibrosis-Evaluation of Benefits, Risks and Recommendations for State Newborn Screening Programs* (Oct 15, 2004 report).<sup>87</sup>

<http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5313a1.htm>

## **Ethnicity**

From the National Cancer Institute (NCI): *Questions and Answers- Fact Sheet on Estimating Cancer Risk in Ashkenazi Jews*.<sup>88</sup> [http://cis.nci.nih.gov/fact/3\\_60.htm](http://cis.nci.nih.gov/fact/3_60.htm)

From the North Carolina Center for Genomics and Public Health (NCCGPH): An online Webcast (2003) entitled: *Molecular Genetics, Race and Health*.<sup>89</sup>

[http://www.sph.unc.edu/nccgph/presentations/pres\\_cooperwebcast.htm](http://www.sph.unc.edu/nccgph/presentations/pres_cooperwebcast.htm)

(Notes: requires RealPlayer).

From the UNC School of Public Health/Minority Health Project/Howard University and others. An on-demand Webcast (2003) entitled: *Genomic Definition of Self and Group Identity: Implications for Biomedical Research*.<sup>90</sup>

[http://www.sph.unc.edu/about/webcasts/2003-06-10\\_mhc/view\\_webcast\\_archive.cfm](http://www.sph.unc.edu/about/webcasts/2003-06-10_mhc/view_webcast_archive.cfm)

(Notes: requires RealPlayer).

From the Pittsburgh Post Gazette, Health and Science Section. An article on genes and race and why some diseases affect certain populations more than others.<sup>91</sup>

<http://www.post-gazette.com/healthscience/20020507hgene0507p3.asp>

## ***Other***

From American College of Medical Genetics (ACMG), American College of Obstetrics and Gynecology (ACOG) and National Human Genome Research Institute (NHGRI): A consensus conference statement entitled: *Laboratory Standards and Guidelines for Population-Based Cystic Fibrosis Carrier Screening* Reprinted in *Genetics in Medicine* 2001; 3:(2):149-54.<sup>92</sup>

<http://www.acmg.net/resources/policies/pol-005.asp>

From the National Institute of General Medical Sciences (NIGMS): *Genes and Populations*. A series of questions and answers on a variety of topics related to genetics in populations.<sup>93</sup>

[http://www.nigms.nih.gov/news/science\\_ed/genepop/](http://www.nigms.nih.gov/news/science_ed/genepop/)

(Notes: available in Spanish).

From the University of North Carolina, Department of Computer Science. A briefing entitled: *Population Genetics Made Simple*. Provides a summary of the concept of population genetics related to evolution.<sup>94</sup>

<http://www.cs.unc.edu/~plaisted/ce/genetics.html>

## **Chronic Disease**

(A selective listing of certain chronic diseases of interest with genetic emphasis).

### ***Cancer-general***

From the National Cancer Institute (NCI): *Cancer Genetics Overview*.<sup>95</sup>

<http://www.nci.nih.gov/cancertopics/pdq/genetics/overview>

### ***Breast and Ovarian Cancer***

From the National Cancer Institute (NCI): *Genetics of Breast and Ovarian Cancer*.<sup>96</sup>

<http://www.nci.nih.gov/cancertopics/pdq/genetics/breast-and-ovarian>

### ***Colorectal Cancer***

From the National Cancer Institute (NCI): *Genetics of Colorectal Cancer*.<sup>97</sup>

<http://www.nci.nih.gov/cancertopics/pdq/genetics/colorectal>

From Genetic Solutions: An online educational program entitled: *The Genetics of Colorectal Cancer*.<sup>98</sup>

<http://www.geneticsolutions.com/PageReq?id=499:13500>

(Notes: CME credit available).

### ***Prostate Cancer***

From the National Cancer Institute (NCI): *Genetics of Prostate Cancer*.<sup>99</sup>  
<http://www.nci.nih.gov/cancertopics/pdq/genetics/prostate>

### ***Obesity***

From the Centers for Disease Control and Prevention (CDC), Office of Genomics and Disease Prevention (OGDP). *Genetics and Obesity: a Public Health Perspective*.<sup>100</sup>  
<http://www.cdc.gov/genomics/info/perspectives/obesity.htm>

Washington Center for Genomics and Public Health, University of Washington (UWCGPH). A slide/audio presentation on the genetics of obesity presented at the Chronic Disease Directors (CDD) teleconference in October, 2004 entitled: The Genetics of Obesity.<sup>101</sup>

<http://depts.washington.edu/cgph/centergoals/obesity.htm>

(Notes: requires PowerPoint and/or audio capabilities).

### ***Diabetes***

From the American Diabetes Association (ADA). *The Genetics of Diabetes*. A comprehensive description of diabetes, prediabetes. Risk assessments are also available at this site.<sup>102</sup>

<http://www.diabetes.org/genetics.jsp>

(Notes: available in Spanish).

From the National Center for Biotechnology Information (NCBI), National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK). *The Genetic Landscape of Diabetes*-This is an online book created in July, 2004 by the NIDDK. Contains extensive information on various forms of diabetes.<sup>103</sup>

<http://www.ncbi.nlm.nih.gov/books/bv.fcgi?call=bv.View..ShowTOC&rid=diabetes.TOC&depth=2>

### ***Asthma***

From the Centers for Disease Control and Prevention (CDC), Office of Genomics and Disease Prevention (OGDP) (2004). Public Health Perspective Series. *Asthma Genomics, Implications for Public Health*.<sup>104</sup>

<http://www.cdc.gov/genomics/info/perspectives/asthma.htm>

From Discovery Health Channel (2000): *The Genetics of Asthma*.<sup>105</sup> An overview of asthma genetics from discovery health.com- an online version of the discovery health channel that patients may be watching.

<http://health.discovery.com/minisites/dna/asthma.html>

### ***Cardiovascular disease***<sup>106</sup>



From the Howard Hughes Medical Institute, BioInteractive, Holiday Lectures on Science Series entitled: *Of Hearts and Hypertension- Blazing a Genetic Trail*. This 4-lecture series looks at several aspects of the genetics of heart disease including hypertension, salt, Includes tools, animations, laboratory activities. <http://www.hhmi.org/biointeractive/cardiovascular/lectures.html>  
(Notes: available free on video, DVD or CD on a variety of topics. Webcast requires RealPlayer. Some tools require QuickTime).

## **Competency 5: Ecogenetics (environmental influences on health/disease, pharmacogenetics/pharmacogenomics)**

*The participant should be able to:*

- *Develop an appreciation for the multiple influences and interactions of environment, lifestyle and genetics in health and predisposition to disease.*
- *Develop an understanding of the basic principles underlying pharmacogenomics and the concept of personalized medicine as it relates to the drug development process, the prescribing process and how genetic variation can influence both therapeutic response to medications and adverse events.*

### **Environmental Influences**

From the Centers for Disease Control and Prevention (CDC), Office of Genomics and Disease Prevention (OGDP)-a *gene-environment interactions* fact sheet.<sup>107</sup>  
<http://www.cdc.gov/genetics/info/files/text/GeneEnviro.pdf>

From the Association of State and Territorial Health Officials (ASTHO). Genetics Brief entitled: *Genes and the Environment*. Covers issues such as interactions between diseases, genes and the environment, research efforts and policy initiatives.<sup>108</sup>  
<http://www.astho.org/pubs/GenesandEnvironmentFINAL.pdf>  
(Notes-requires Adobe Acrobat Reader).

### **Pharmacogenomics**

From the National Center for Biotechnology Information (NCBI). Entitled: *One Size Does Not Fit All, The Promise of Pharmacogenomics*. A science primer on

pharmacogenomics containing a series of questions and answers about pharmacogenetics/pharmacogenomics.<sup>109</sup>  
<http://www.ncbi.nlm.nih.gov/About/primer/pharm.html>

From National Institute of General Medical Sciences (NIGMS): An online brochure entitled: *Medicines for You*. Describes the basic concept of pharmacogenomics and its relationships to medication effects, both positive and negative.<sup>110</sup> <http://www.nigms.nih.gov/funding/medforyou.html>  
(Notes: Available in Spanish).

From the Journal Nature: *Pharmacogenetics and the Practice of Medicine*.<sup>111</sup>  
<http://genetics.gsk.com/docs/RosesNature.pdf>  
(Notes: requires Adobe Acrobat Reader).

From the Journal Future Drugs: Expert Reviews in Molecular Diagnostics (2001)  
An article entitled: *Pharmacogenetics: the Rx Perspective*.<sup>112</sup>  
<http://genetics.gsk.com/docs/Manascob.pdf>  
(Notes: requires Adobe Acrobat Reader, authors from GlaxoSmithKline).

From the American Association for Clinical Chemistry (AACC), sponsored by an educational grant from Bayer Diagnostics, An educational slide set (html) describing pharmacogenetic/genomic research in industry, entitled:  
*Pharmacogenetics: A Prescription for Industry?*<sup>113</sup>  
<http://www.aacc.org/access/pharmacogenomics/>  
(Notes: presenter from Pharsight Corporation).

## Competency 6: Family History

*The participant should be able to:*

- *Develop the understanding, knowledge and abilities necessary to gather an accurate family history (pedigree) including how to elicit individual, family, medical, developmental and reproductive history.*
- *Develop an understanding of how to most effectively evaluate and communicate individual and family risk in an appropriate manner and recognize when it is important to refer to a genetic professional.*

- *Develop an awareness of available tools, forms, worksheets and other resources to aid in the appropriate initial collection of family health history as well as updating the family history at regular intervals.*
- *Determine mode of inheritance and risk of transmission of disease/conditions to offspring for relevant conditions.*

From the Centers for Disease Control and Prevention (CDC), Office of Genomics and Disease Prevention (OGDP). *Family History for Preventive Medicine and Public Health*. Several family history tools -Family History Public Health Initiative. This site has a family history tool, a fact sheet describing the family history initiative and a public health perspective outlining the importance of family history to public health.<sup>114,115</sup> Extensive links to related publications, websites on family history.

<http://www.cdc.gov/genomics/activities/famhx.htm>

<http://www.cdc.gov/genomics/info/perspectives/famhistr.htm>

(Notes: requires PowerPoint, all pages available in Spanish).

From the National Society of Genetic Counselors (NSGC), this is a site that helps consumers develop their own family tree (good for health care providers too). Provides step-by-step guidance on important information to gather when developing a family tree and a detailed explanation of how to draw a pedigree (family tree).<sup>116</sup>

<http://www.nsgc.org/consumer/familytree/index.asp>

[http://www.nsgc.org/consumer/familytree/tree\\_images.asp](http://www.nsgc.org/consumer/familytree/tree_images.asp)

From the United States Department of Health and Human Services (US DHHS), Office of Surgeon General. *My Family Health Portrait* is a software program available for free that can be downloaded to help create a family health tree. A PDF version is also available for printing.<sup>117</sup>

<http://www.hhs.gov/familyhistory/>

(Notes: requires Winzip, also may require RealPlayer to view Webcast on the family history initiative).

From the American Medical Association, (AMA): *Family History Tools* contains several resources including sections on the importance of gathering a family history, prenatal genetic screening questionnaire, pediatric clinical genetics questionnaire, and adult family history form.<sup>118</sup>

<http://www.ama-assn.org/ama/pub/category/2380.html>

[http://www.ama-assn.org/ama1/pub/upload/mm/464/family\\_history02.pdf](http://www.ama-assn.org/ama1/pub/upload/mm/464/family_history02.pdf)

(Notes: An eight-page pamphlet: *A family medical history in disease prevention* is available free by contacting AMA or on the website. Requires Adobe Acrobat Reader).

From the Genetics Education Program for Nurses (GEPN) at the University of Cincinnati, Children's Hospital. An online self-paced study module entitled: *Interpreting Family History*<sup>119</sup>

<http://www.cincinnatichildrens.org/ed/clinical/gpnf/ce/skill/default.htm>

(Notes: Registration required and course is free but \$ for CE. Other modules available).

From the Arthur G. James Cancer Hospital at Ohio State University, *Cancer Genetics Workbook, Building and Understanding Your Family Medical History*. This is a guide for patients which includes a questionnaire on cancer risk assessment.<sup>120</sup>

<http://www.jamesline.com/patientsandpublic/prevention/cancergeneticsworkbook/>

From the American Academy of Family Physicians. An online 2005 CME program on Family History through the Annual Clinical Focus (ACF)<sup>121</sup>

<http://www.aafp.org/x30165.xml>

## **Competency 7: Risk Assessment and Communication**

(Identification of high risk patients, appropriate referrals, cultural sensitivity, risk management tools).

*The participant should be able to:*

- *Identify populations at high risk of genetic predisposition to disease, assess risk and communicate risk in a culturally appropriate manner.*
- *Describe the role and training of a genetic counselor and gain an understanding of who, when and how to refer to genetic counseling services.*
- *Be able to identify community resources and professional societies for genetic counseling as well as local genetic counseling programs and services.*

## **Risk Assessment/Communication**

From the Journal *The Oncologist* entitled: *Communicating Genetic Risk: Pro's Cons and Counsel*. (2000) A case study relating to the communication of genetic risk.<sup>122</sup> <http://theoncologist.alphamedpress.org/cgi/reprint/5/2/152>

From the National Cancer Institute (NCI) *Cancer Genetics Risk Assessment and Counseling*-A great guide covering a variety of topics on counseling patients about cancer and explaining risk assessment.<sup>123</sup>  
<http://www.cancer.gov/cancerinfo/pdq/genetics/risk-assessment-and-counseling>

From the National Cancer Institute (NCI): *Cancer Genetics Service Directory*-A directory which lists professionals who provide services related to cancer genetics (cancer risk assessment, genetic counseling, genetic susceptibility testing, and others).<sup>124</sup> <http://www.cancer.gov/search/geneticsservices/>  
(Notes: These professionals have applied to be listed in this directory).

From the Harvard Center for Cancer Prevention: *Colorectal Cancer: A Risk Management Guide for Health Care Professionals*. A two page report outlining recommendations for risk management with a risk management checklist.<sup>125</sup>  
[http://www.hsph.harvard.edu/cancer/crc/downloads/CRC\\_guide.pdf](http://www.hsph.harvard.edu/cancer/crc/downloads/CRC_guide.pdf)  
(Notes: Requires Adobe Acrobat Reader).

From the Harvard Center for Cancer Prevention: *What's Your Disease Risk?*- An interactive risk assessment calculator which determines your risk of various diseases including many cancers and what you can do to decrease your risk.<sup>126</sup>  
<http://www.yourdiseaserisk.harvard.edu/>  
(Notes: You can change various modifiable risk factors and watch the effects on your risk).

## **Genetic Counseling and Referrals**

From GeneticSolutions: An online educational program on Genetic Counseling entitled: *Introduction to Genetic Counseling*.<sup>127</sup>  
<http://www.geneticsolutions.com/PageReq?id=675:8758>  
(Notes, CE, CME credit available).

From GeneTests: A Primer entitled: *About Genetics Services*: Covers a variety of questions about genetic services, including who should have genetic tests.<sup>128</sup>  
<http://www.geneclinics.org/servlet/access?id=8888892&key=zmz5f4T8wEeK2&fcn=y&fw=y&filename=/concepts/primer/primerintro.html>

From the National Society of Genetic Counselors (NSGC)- Provides a link allowing you to locate a genetic counselor near you (nationwide)- Contains search functions that allows searching by zip code, state, distance, area of specialization.<sup>129</sup>  
<http://www.nsgc.org/resourcelink.asp>

From Mountain States Genetics Network (MoStGeNe): A brief guide listing the circumstances in which to refer patients to a genetic counselor entitled:

*Indications for Genetic Counseling Referrals.*<sup>130</sup>

<http://www.mostgene.org/dir/indicate.htm>

From the University of Medicine and Dentistry of New Jersey: A clinical services guide entitled: *Indicators for Genetic Service Referral.*<sup>131</sup>

[http://www.umdnj.edu/genesatwork/clinicalserv/02\\_indicators\\_genetic.htm](http://www.umdnj.edu/genesatwork/clinicalserv/02_indicators_genetic.htm)

## Competency 8: Basic Medical/Clinical Genetics

*The participant should:*

- *Develop an understanding of the concepts, roles and relationships between genes, chromosomes, DNA, RNA, proteins, nucleotides, base pairs, amino acids, codons, triplets, haplotype, genotype, phenotype, genetic code and the double helix.*
- *Develop an understanding of inheritance patterns, including autosomal dominant and autosomal recessive traits, single, multiple and X-linked diseases.*
- *Understand processes of transcription, translation, meiosis, mitosis, somatic and germ line mutations, polymorphisms, transpositions, deletions, mutations, transgenic and cloning initiatives such as Dolly the sheep and CC the cat.*
- *Understand the laboratory techniques most commonly used in identifying genetic sequences including, Polymerase chain reaction (PCR), Fluorescent in-situ hybridization (FISH), Southern blotting and chromosome maps.*
- *Develop an understanding of the genetics of common chronic diseases and the multifactorial role of genetics, environment, lifestyle factors in disease predisposition and acquisition.*

From GlaxoSmithKline: *Understanding Genetics* -An online multimedia educational resource on genetics for health care providers and consumers. Includes information about pharmacogenomics/pharmacogenetics, bioinformatics, implementing genetics in clinical practice and a library of resources for healthcare

providers and interactive, animated explanations for genetics education on consumer site.<sup>132,133</sup>

<http://genetics.gsk.com/healthcare.htm>

[http://genetics.gsk.com/generalpublic\\_flash.htm](http://genetics.gsk.com/generalpublic_flash.htm) (for consumers)

(Notes: available on CD-ROM, free of charge, consumer site is interactive and requires Macromedia FlashPlayer).

From Roche Laboratories, Genetics Education Program; A multimedia online or CD-ROM on basic clinical genetics for health care providers and the public entitled: *Clinical Genetics*. Includes information on finding genes associated with diseases, genetics of common complex disorders, pharmacogenetics and ethical, legal and social issues.<sup>134</sup> Teachers manual and presentation tool also available.

[http://www.roche.com/home/science/sci\\_gengen/sci\\_gengen\\_cdrom.htm](http://www.roche.com/home/science/sci_gengen/sci_gengen_cdrom.htm)

(Notes: Online as zip file, requires WinZip, Macromedia FlashPlayer, multilingual).

From Dartmouth Medical School, Interactive Media Lab. A CME program (online or CD-ROM) entitled: *Genetics in Clinical Practice: A Team Approach*.

An interactive media program of a Virtual Genetics Clinic (Mini fellowship) which guides the learner through many topics in genetics using a simulated virtual genetics clinic.<sup>135</sup>

<http://www.iml.dartmouth.edu/education/cme/Genetics/>

(Notes: CME available up to 10 hours, requires multiple plug ins).

From Cincinnati Children's Medical Center, Genetics Education Program for Nurses (GEPN). An online multimedia learning program entitled: *Mendelian Inheritance-Meiosis Connection*.<sup>136</sup>

<http://www.cincinnatichildrens.org/ed/clinical/gpnf/resources/curriculum/mendelian.htm>

(Notes: Requires Macromedia FlashPlayer).

From the Dolan DNA Learning Center (DDNALC), Cold Spring Harbor Laboratories (CSHL): A multimedia guide to a variety of genetic disorders entitled: *Your Genes, Your Health*. Pick from a variety of diseases and roll over sections on inheritance, causes, symptoms, incidence, treatment, testing.<sup>137</sup>

<http://www.ygyh.org>

(Notes: Additional resource information on diseases is available from the companion site, DNA from the Beginning).

From the Centers for Disease Control and Prevention (CDC), Office of Genomics and Disease Prevention (OGDP) and the three Centers for Genomics and Public Health: An audio/video presentation entitled: *Genomics for Public Health Practitioners*. Intended to create an awareness of genomics in public health for practitioners with minimal experience in genomics.<sup>138</sup>

<http://www.cdc.gov/genomics/training/GPHP/default.htm>



(Notes: (requiresMacromedia FlashPlayer, power-point, audio). Serves as basis for introduction to the **Six Weeks to Genomic Awareness series**). See next.

From Universities of Michigan, North Carolina and Washington, Centers for Genomics and Public Health, in collaboration with the CDC: ***Six Weeks to Genomic Awareness*** is a series of web-based presentations on the importance of genetics to public health.<sup>139</sup> It was designed to provide public health professionals with a foundation for understanding genomic advances and identifying the relevance of genomics to public health. Topics include: *introduction to genomics, genetic testing, basic clinical genetics, ethical issues in genetics, gene-environment interactions, pharmacogenomics, genes in populations and state and local resources.*

<http://www.genomicawareness.org/index.htm>

(Notes: requires Webcast viewing capabilities-video/audio).

From Cold Spring Harbor Laboratory (CSHL), Dolan DNA Learning Center (DDNALC): A Biology Animation Library- Contains animations of common biology and genetic concepts and laboratory methods. Topics covered include polymorphisms, transpositions, cycle sequencing, Southern Blots, Polymerase chain reaction (PCR), and more.<sup>140</sup>

<http://www.dnalc.org/resources/BiologyAnimationLibrary.htm>

(Notes: requires Shockwave).

From Science Museum in the UK. A UK online science museum exhibit detailing the history of *the Cloning of Dolly the Sheep*.<sup>141</sup>

<http://www.sciencemuseum.org.uk/antenna/dolly/index.asp>

From National Geographic News: *CC the cloned cat: Scientist successfully clone cat*. A news article from 2002 describing the steps and science leading to the cloning of CC the cat.<sup>142</sup>

[http://news.nationalgeographic.com/news/2002/02/0214\\_021402copycat.html](http://news.nationalgeographic.com/news/2002/02/0214_021402copycat.html)

From a collaborative effort of National Center for Biotechnology Information (NCBI) and Johns Hopkins University: Online Mendelian Inheritance in Man (**OMIM™**): A comprehensive searchable database containing information on a variety of disorders with genetic components.<sup>143</sup>

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM>

## Competency 9: Genetic Testing

*The participant should*

- *Develop an awareness of the different types of genetic tests including those used for pre-symptomatic and susceptibility testing, prenatal screening, newborn testing and carrier testing as well as indications for genetic testing.*
- *Develop an understanding of the issues involved in the costs of genetic testing, risks, benefits and limitations of genetic tests.*

From the National Cancer Institute (NCI): A Web-based tutorial entitled: *Understanding Gene Testing*.<sup>144</sup>

<https://cissecure.nci.nih.gov/ncipubs/details.asp?pid=231>

From Access Excellence at the National Health Museum- funded by Department of Health and Human Services (DHHS)- A glossary entitled: *Understanding Gene Testing*. Describes terms used in genetic testing.<sup>145</sup>

<http://www.accessexcellence.org/AE/AEPC/NIH/gene27.html>

From GeneticHealth: The *Genetic Testing Process: A Case Study*. Covers when a genetic test is appropriate, testing, counseling, getting the results, disclosing results to other family members, follow-up medical care using a case-study based approach.<sup>146</sup>

[http://www.genetichealth.com/GT\\_Genetic\\_Testing\\_Case\\_Study\\_The\\_Testing\\_Process.shtml](http://www.genetichealth.com/GT_Genetic_Testing_Case_Study_The_Testing_Process.shtml)

From the Centers for Disease Control and Prevention (CDC), Office of Genomics and Disease Prevention (OGDP) A report entitled: *Public Health Impact of Genetic Tests at the End of the 20<sup>th</sup> Century*.<sup>147</sup> From the Journal *Genetics in Medicine* 2001.

<http://www.cdc.gov/genomics/info/reports/files/print/gim3-6-405.pdf>

(Notes Requires Adobe Acrobat Reader)

From the Genetics and Public Policy Center at Johns Hopkins A video-cast of a preimplantation genetic diagnosis (PGD forum) entitled: *Preimplantation Genetic Diagnosis- Custom Kids: Genetic Testing of Embryos*.<sup>148</sup>

<http://www.dnapolicy.org/policy/pgdForum.jhtml>

(Notes: Requires Windows MediaPlayer to view video, Adobe Acrobat Reader to view pdf file).

From the Genetics and Public Policy Center at Johns Hopkins University: The final report: entitled: *Reproductive Genetic Testing: Issues and Options for Policymakers*.<sup>149</sup> <http://tools-content.labvelocity.com/pdfs/5/66755.pdf>

## **Competency 10: Community and Public Health**

**Resources** (Aid to locating genetic counseling professionals, genetic services, laboratory services, resources related specifically to genomics and public health, guidelines for web browsing and locating sources of genomic information).

*The participant should be able to:*

- *Develop the skills necessary to locate available state, local and national resources related to genomics and disease including genetics professionals/counselors, appropriate support groups, genetic testing laboratories.*
- *Identify sources of genomic information that are multilingual and culturally appropriate.*
- *Use the internet to locate sources of training and educational opportunities and materials in genomics for public health practitioners.*

## **Resources**

From the University of Michigan Center for Genomics and Public Health (UMCGPH) one of three nationwide centers in the U.S., funded for 3 years through mid 2005 by Centers for Disease Control and Prevention (CDC) and Association of Schools of Public Health (ASPH). Broad goals include increasing the genomics and public health knowledge base with a special focus on cardiovascular disease, to provide technical assistance to state, regional, and local public health entities in the integration of genomics into public health practice and

to train members of the current and future workforce in genomics.<sup>150</sup>

<http://www.sph.umich.edu/genomics/index.html>

From the University of Washington Center for Genomics and Public Health (UWCGPH) one of three nationwide centers in the U.S., funded for 3 years through 2005 by CDC/ASPH. Broad goals include the integration of advances in genetic technology into public health practice and offer research and educational opportunities for public health students and professionals with a special focus on asthma, diabetes, familial hypercholesterolemia. Attention in identifying practical applications of this knowledge to public health practice, Provide technical assistance to local, state, and regional public health organizations and to develop and provide training for the current and future public health workforce.<sup>151</sup>

<http://depts.washington.edu/cgph/>

From the Coalition of State Genetics Coordinators (CSGC) -An organization of state and territorial genetics coordinators and others who support the mission to promote core public health functions as they apply to genetics.<sup>152</sup>

<http://www.stategeneticscoordinators.org/index.html>

From the Division of Public Health, Office of Genomics, *The North Carolina State Plan for Genomics and Public Health* (January, 2004).<sup>153</sup>

<http://www.communityhealth.dhhs.state.nc.us/Genomics/Annual%20Report.pdf>  
(Notes: requires Adobe Acrobat Reader).

From the Centers for Disease Control, Office of Genomics and Disease Prevention (CDC/OGDP): *Genomics and Population Health: United States 2003*. A comprehensive report illustrating examples for how public health is beginning to address three major gaps along the genomics “translation highway” including conducting genomics and population health research, developing evidence on the value of genomic information, and integrating genomic information in practice and programs.<sup>154</sup> <http://www.cdc.gov/genomics/activities/ogdp/2003.htm>

From the University of North Carolina (UNC) School of Public Health (SPH)/CDC: Public Health Grand Rounds (archived Webcast) entitled: *Genetics and Public Health: the Future is Now*. Illustrates what genetic research has to do with public health.<sup>155</sup>

<http://www.publichealthgrandrounds.unc.edu/genetics/index.htm>

(Notes: requires RealPlayer).

From the University of North Carolina (UNC), School of Public Health (SPH)/CDC, North Carolina Center for Genomics and Public Health (NCCGPH): Public Health Grand Rounds-(archived Webcast) entitled:- *The Genomics Revolution and Public Health* -covers a variety of issues on genetics/genomics of relevance to public health practitioners.<sup>156</sup>

<http://www.sph.unc.edu/nccgph/phgenetics/index.htm>

From the Association of State and Territorial Health Officials (ASTHO). A publication entitled: *Genomics: A Guide for Public Health*. This is a guide aimed at public health practitioners and contains a toolkit, workbook and resources to aid in the integration of genomics in public health practice.<sup>157</sup>  
<http://www.genomicstoolkit.org/index.shtml>

### **Training/Education**

From the Public Health Foundation (PHF), *TRAIN (training real time affiliated integrated networks)* is a searchable database of training programs via *Trainingfinder*, to help public health professionals find training opportunities based on core public health competencies.<sup>158</sup>

<https://www.train.org/DesktopShell.aspx>

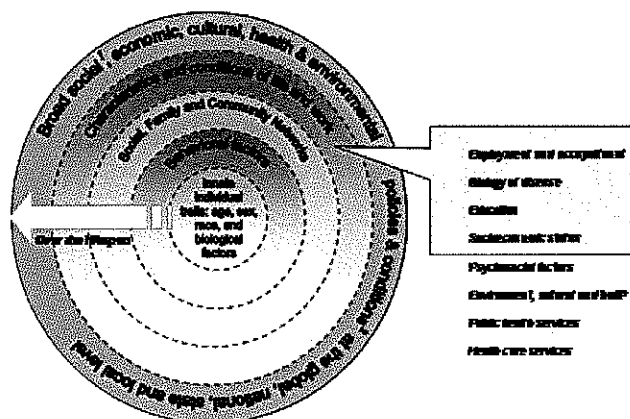
From the Council on Linkages between Academia and Public Health Practice- (the competencies <http://www.trainingfinder.org/competencies/list.htm>

(Notes: training program is on a secure server, you may access through the competencies site. If a note about “security issues” appears when clicking directly on the site. registration is required, but its free).

From the North Carolina Institute of Public Health (NCIPH) and Southeast Public Health Training Center (SPHTC), a searchable database/clearinghouse of training programs, materials, resources for public health professionals entitled: *AskSphere (Southeast Public Health Educational Resource for Enhancement)*.<sup>159</sup>  
<http://www.asksphere.org/>

## Appendix 1. The Ecological View of Health from a Public Health Perspective<sup>3</sup>

### Determinants of Population Health



THE NATIONAL ACADEMIES  
Advisers to the Nation on Science, Engineering, and Medicine

INSTITUTE OF MEDICINE

## Appendix 2. The Ecological View of Health from a Consumer Perspective<sup>4</sup>

### Determinants of Health & Disease



*George Burns 1896-1996*

#### Keys to Longevity:

- ◆ Cigars
- ◆ Afternoon naps
- ◆ Bridge with buddies
- ◆ A couple of martinis each day



### Appendix 3. Examples of Media Coverage of Genomics (Time Magazine)



---

## REFERENCES

- <sup>1</sup> U.S. Department of Health and Human Services. Healthy People 2010: Understanding and Improving Health. (November 2000) 2<sup>nd</sup> ed. Washington, DC. Government Printing Office. [Electronic version]. Retrieved March 15, 2005 from <http://www.healthypeople.gov/Publications>
- <sup>2</sup> Evans, R.G., Stoddart, G.L. (1990). Producing Health, Consuming Healthcare. *Soc Sci Med* 31(12):1347-1363.
- <sup>3</sup> Institute of Medicine (November 11, 2002) The Future of the Public's Health in the 21<sup>st</sup> Century Washington DC. National Academy Press. Retrieved March 5, 2005 from <http://books.nap.edu/catalog/10548.html>
- <sup>4</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention. (March 3, 2004) Workforce Training- Determinants of Health and Disease [powerpoint slides]. Retrieved March 5, 2005 from <http://www.cdc.gov/genomics/training/competencies/files/slides/workforceTraining.ppt>
- <sup>5</sup> Institute of Medicine (1988) The Future of Public Health. [Electronic version] Washington, D.C., National Academy Press. Retrieved March 15, 2005 from <http://www.nap.edu/books/0309038308/html/index.html>
- <sup>6</sup> Institute of Medicine (2002). The Future of the Public's Health in the 21<sup>st</sup> Century. [Electronic version]. Washington, D.C., National Academy Press. Retrieved March 15, 2005 from <http://books.nap.edu/catalog/10548.html>
- <sup>7</sup> Hernandez L. ed. Institute of Medicine. (2003) Who Will Keep the Public Healthy? Workshop Summary. [Electronic Version] Washington, D.C., National Academy Press. Retrieved March 15, 2005 from <http://books.nap.edu/catalog/10759.html>
- <sup>8</sup> Gebbie, K., Rosenstock, L., and Hernandez, L., Institute of Medicine (2003). Who Will Keep the Public Healthy? Educating Public Health Professionals for the 21<sup>st</sup> Century. [Electronic version]. Washington, D.C., National Academy Press. Retrieved March 15, 2005 from <http://books.nap.edu/catalog/10542.html>
- <sup>9</sup> Centers for Disease Control and Prevention, Office of Workforce Policy and Planning (September, 2, 2004). The Public Health Workforce Development Initiative. Retrieved March 7, 2005 from <http://www.phppo.cdc.gov/owpp/workforcedev.asp>



- 
- <sup>10</sup> Office of Workforce Policy and Planning, CDC. Strategy 2: Identify Competencies/Develop Curriculum. Retrieved March 15, 2005 from [http://www.phppo.cdc.gov/owpp/WDI\\_Identify.asp](http://www.phppo.cdc.gov/owpp/WDI_Identify.asp)
- <sup>11</sup> Gebbie, K., Health Resource Services Administration, Bureau of Health Professions (November 2000). National Center for Health Workforce Information and Analysis. The Public Health Workforce: Enumeration 2000. [Electronic Version]. Retrieved March 15, 2005 from <ftp://ftp.hrsa.gov/bhpr/nationalcenter/phworkforce2000.pdf>
- <sup>12</sup> U.S. Department of Health and Human Services (n.d.). The Public Health Workforce: An Agenda for the 21<sup>st</sup> Century. A Report of the Public Health Functions Project. Retrieved March 15, 2005 from <http://www.health.gov/phfunctions/pubhlth.pdf>
- <sup>13</sup> U.S. Department of Health and Human Services, Bureau of Health Professions. (January 2005) Public Health Workforce Study. Retrieved March 27, 2005 from <http://bhpr.hrsa.gov/healthworkforce/reports/publichealth/default.htm>
- <sup>14</sup> Association of State and Territorial Health Officials (2004) State Public Health Employee Worker Shortage: A Civil Service Recruitment and Retention Crisis. [Survey]. Retrieved March 5, 2005 from <http://www.astho.org/pubs/workforce-survey-Report-2.pdf>
- <sup>15</sup> Cooksey, J.A. (February 2000). The Genetic Counselor Workforce. Illinois Center for Health Workforce Studies. Chicago, IL. Retrieved March 5, 2005 from <http://www.uic.edu/sph/irhwc/gen%20counc%20wf%20jc.pdf>
- <sup>16</sup> Personal Communication, Elizabeth Balkite, M.S., CGC, Executive Director; American Board of Genetic Counseling. April 1, 2005.
- <sup>17</sup> Begleiter, M.L., Training for Genetic Counselors (2002). Nature Reviews Genetics 3;557-561.
- <sup>18</sup> American Public Health Association. The Essential Services of Public Health. Retrieved March 27, 2005 from <http://www.apha.org/ppp/science/10ES.htm#monitor>
- <sup>19</sup> Khoury M. The Integration of Genetics into Public Health: A Blueprint. (2000). [Image]. Retrieved March 3, 2005 from <http://www.cdc.gov/genomics/training/competencies/history.htm>
- <sup>20</sup> Austin M.A., Peyser, P.A., and Khoury, M.J., The Interface of Genetics and Public Health: Research and Educational Challenges. (2000). Annu Rev Public Health 21:81-99.
- <sup>21</sup> Hoyert, D.L., Kung, H., and Smith, B.L., National Vital Statistics Reports

---

(2005). Deaths: Preliminary Data for 2003. 53(15):p3 [Electronic Version]  
Retrieved on March 7, 2005 from  
[http://www.cdc.gov/nchs/data/nvsr/nvsr53/nvsr53\\_15.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr53/nvsr53_15.pdf)

<sup>22</sup> Shortell, S.M., Weist, E.M., Sow, Mah-Sere, K.S., Foster A., Tahir, R.,  
Implementing the IOM-Recommended Curriculum Content in Schools of Public  
Health: A Baseline Assessment(2004). Am J Public Health 94(10):1671-4.

<sup>23</sup> U.S. Department of Health and Human Services. Presidents Budget Proposal  
for FY 2006. Retrieved March 19, 2005 from  
<http://www.dhhs.gov/budget/06budget/FY2006BudgetinBrief.pdf>

<sup>24</sup> Centers for Disease Control and Prevention. (2005) State of CDC 2004:  
Protecting Health for Life. Retrieved March 17, 2005 from  
[http://www.cdc.gov/od/oc/media/pressrel/ProtectingHealth\\_ForLife\\_04.pdf](http://www.cdc.gov/od/oc/media/pressrel/ProtectingHealth_ForLife_04.pdf)

<sup>25</sup> Ojha, R.P., and Thertulien, R. (2005). Health Care Policy Issues as a Result of  
the Genetic Revolution: Implications for Public Health. Am J Public Health  
95(3):385-388.

<sup>26</sup> Feters, M.D., Doukas, D.J., and Phan, K.L., (1999) Family Physicians'  
Perspectives on Genetics and the Human Genome Project. Clinical Genetics  
56(1):28-34.

<sup>27</sup> Suther,S., and Goodson, P., (2003) Barriers to the Provision of Genetic Services  
by Primary Care Physicians:A Systematic Review of the Literature. Genetics in  
Medicine. 5(2):70-76.

<sup>28</sup> Acheson, L., (2003). Fostering Application of Genetics in Primary Care: What  
Will it Take? [Editorial]. Genetics in Medicine 5(2):63-65.

<sup>29</sup> U.S. Department of Health and Human Services, Office of the Surgeon General  
(December 29, 2004) Family History Initiative-My Family Health Portrait  
[Family history software]. Retrieved March 5, 2005 from  
<http://www.hhs.gov/familyhistory/>

<sup>30</sup> National Coalition for Health Professional Education in Genetics (n.d.). Genetic  
Family History Resources. Retrieved March 27, 2005 from  
<http://www.nchpeg.org>

<sup>31</sup> American Medical Association (March 25, 2005). Family History Tools.  
Retrieved March 27, 2005 from  
<http://www.ama-assn.org/ama/pub/category/2380.html>

<sup>32</sup> American Academy of Family Physicians. Annual Clinical Focus 2005. Family  
History CME Video Program. Retrieved March 27, 2005 from  
<http://www.aafp.org/x30165.xml>

---

<sup>33</sup> Centers for Disease Control and Prevention. Office of Genomics and Disease Prevention. (March 2, 2005) Family History Initiatives. Retrieved March 27, 2005 from <http://www.cdc.gov/genomics/fHix.htm>

<sup>34</sup> National Society of Genetic Counselors (n.d.). Retrieved March 5, 2005 from <http://www.nsgc.org>

<sup>35</sup> Rainie, L., The Pew Internet & American Life Project. (2005). Internet: The Mainstreaming of Online Life. Retrieved March 19, 2005 from [http://www.pewinternet.org/pdfs/Internet\\_Status\\_2005.pdf](http://www.pewinternet.org/pdfs/Internet_Status_2005.pdf)

<sup>36</sup> Rainie, L., The Online Healthcare Revolution. Presented at the Internet Librarian Conference, November, 2, 2003, Monterey, CA. [Slide presentation] Retrieved March 19, 2005 from [http://www.pewinternet.org/PPF/r/22/presentation\\_display.asp](http://www.pewinternet.org/PPF/r/22/presentation_display.asp)

<sup>37</sup> Competency-to-Curriculum Toolkit: Developing Curricula for Public Health Workers. Center for Health Policy (October 2004), Columbia University School of Nursing and Association of Teachers of Preventive Medicine. Retrieved March 27, 2005 from [http://www.atpm.org/publications/Compt to Curric Toolkit.pdf](http://www.atpm.org/publications/Compt_to_Curric_Toolkit.pdf)

<sup>38</sup> Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry. Strategic Plan for Public Health Workforce Development 2000. Retrieved March 27, 2005 from <http://www.phppo.cdc.gov/owpp/docs/library/2000/Strategic%20Plan%20for%20PH%20WD%20Exec%20Sum.pdf>

<sup>39</sup> Lapham, V.E., Kozma, C., Weiss, J.O., Benkendorf, J.L., and Wilson, M.A., (2000). The Gap Between Practice and Genetics Education of Health Professionals: HuGEM Survey Results. *Genetics in Medicine* 2(4):226-231.

<sup>40</sup> Core Competency Working Group of the National Coalition for Health Professional Education in Genetics (2001). Recommendations of Core Competencies in Genetics Essential for All Health Professionals. [Committee Report]. *Genetics in Medicine*;3(2):155-159.

<sup>41</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention (March 2, 2005) Public Health Workforce Development: Developing Genomic Competencies in Public Health. Retrieved March 5, 2005 from <http://www.cdc.gov/genomics/training/competencies/project.htm>

<sup>42</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention. (March 2, 2005), Genomics Workforce Competencies 2001. Retrieved March 3, 2005 from <http://www.cdc.gov/genomics/training/competencies/comps.htm>

- 
- <sup>43</sup> National Coalition for Health Professional Education in Genetics. NCHPEG Core Competencies. Retrieved March 5, 2005 from <http://www.nchpeg.org/nchpeg.html?http://www.nchpeg.org/eduresources/core/core.asp>
- <sup>44</sup> American Academy of Family Physicians, (February 1999). Medical Genetics. Retrieved March 3, 2005 from <http://www.aafp.org/x16547.xml>
- <sup>45</sup> American Society for Human Genetics (December 27, 2001). Medical School Core Curriculum in Genetics. Retrieved March 3, 2005 from <http://genetics.faseb.org/genetics/ashg/policy/rep-01.htm>
- <sup>46</sup> Association of State and Territorial Health Officials. Policy Position Statements, Public Health Genetics (n.d.). Retrieved March 3, 2005 from [http://www.astho.org/pubs/consolidatedpolicy.html#PHG-1\\_PubHealthGenetics](http://www.astho.org/pubs/consolidatedpolicy.html#PHG-1_PubHealthGenetics)
- <sup>47</sup> Association of State and Territorial Chronic Disease Directors (March 2002) Genomics and Chronic Disease Summit. Retrieved March 3, 2005 from [http://www.chronicdisease.org/Genomics\\_Summit\\_Report.pdf](http://www.chronicdisease.org/Genomics_Summit_Report.pdf)
- <sup>48</sup> University of Michigan, Public Health Genetics An Education Model (n.d.). Retrieved March 3, 2005 from <http://www.sph.umich.edu/geneticsed/>
- <sup>49</sup> University of Washington, School of Public Health. Public Health Genetics Competencies. Retrieved March 5, 2005 from <http://depts.washington.edu/phgen/DegreeTracks/competencies.html>
- <sup>50</sup> University of Pittsburg, School of Public Health, MPH in Public Health Genetics. Retrieved March 5, 2005 from <http://www.hgen.pitt.edu/academics/mph.html>
- <sup>51</sup> American Board of Genetic Counseling Inc., Required Criteria for Graduate Programs in Genetic Counseling Seeking Accreditation by the American Board of Genetic Counseling. (November, 3, 2004). Retrieved April 3, 2005 from [http://www.abgc.net/genetics/abgc/accred/acc-03/2004\\_Required\\_AC\\_Criteria.pdf](http://www.abgc.net/genetics/abgc/accred/acc-03/2004_Required_AC_Criteria.pdf)
- <sup>52</sup> North Carolina Center for Genomics and Public Health (NCCGPH) (n.d.). [Mission statement]. Retrieved February 17, 2005 from <http://www.sph.unc.edu/nccgph/mission.htm>
- <sup>53</sup> Health on the Net Foundation: The HONcode. Retrieved March 7, 2005 from <http://www.hon.ch/HONcode/Trustworthy.html#HONcode>
- <sup>54</sup> National Library of Medicine (May 3, 2004) MedLine Plus Guide to Healthy Web Surfing. Retrieved March 7, 2005 from <http://www.nlm.nih.gov/medlineplus/healthywebsurfing.html>

- 
- <sup>55</sup> National Library of Medicine (March 2, 2005) Evaluating Health Information. Retrieved March 7, 2005 from <http://www.nlm.nih.gov/medlineplus/evaluatinghealthinformation.html>
- <sup>56</sup> National Coalition for Health Professional Education in Genetics. Genetics Resources on the Web [database]. Retrieved April 3, 2005 from <http://www.geneticsresources.org>
- <sup>57</sup> Cold Spring Harbor Laboratories (2003), DNA Interactive. Timeline [Interactive Timeline]. Retrieved February 9, 2005 from <http://www.dnai.org/timeline/index.html>
- <sup>58</sup> National Institutes of Health, Stetton Museum of Medical Research. [Online Museum Exhibit] Deciphering the Genetic Code. Retrieved February 9, 2005 from <http://history.nih.gov/exhibits/nirenberg/index.htm>
- <sup>59</sup> Discovery Channel, Discovery Health. (February 12, 2001) The History of Modern Genetics. Retrieved February 17, 2005 from [http://health.discovery.com/minisites/dna/zw\\_history.html](http://health.discovery.com/minisites/dna/zw_history.html)
- <sup>60</sup> National Human Genome Research Institute. National DNA Day. April 2003. (January 2005). [Webcasts]. Retrieved February 17, 2005 from <http://www.genome.gov/10506367>
- <sup>61</sup> Kaiser Network Health-Casts (April 15, 2003): [Webcast] Bringing the Genome to You: Human Genome Project to Society. Retrieved February 17, 2005 from [www.kaisernetwork.org/healthcast/nhgri/15apr2003/](http://www.kaisernetwork.org/healthcast/nhgri/15apr2003/)
- <sup>62</sup> National Human Genome Research Institute (October 2004) Fifty Years of DNA: From Double Helix to Health. [Webcasts]. Retrieved February 17, 2005 from <http://www.genome.gov/10005139>
- <sup>63</sup> U.S. Department of Energy, The Human Genome Project (March 2003). Genomics and its Impact on Science and Society. A 2003 Primer. (2003). Retrieved February 17, 2005 from [http://www.ornl.gov/sci/techresources/Human\\_Genome/publicat/primer2001/index.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/publicat/primer2001/index.shtml)
- <sup>64</sup> Dolan DNA Learning Center, Cold Spring Harbor Laboratories (n.d.). Image Archive on the American Eugenics Movement. [database]. Retrieved February 17, 2005 from <http://www.eugenicsarchive.org/eugenics/>
- <sup>65</sup> National Human Genome Research Institute (n.d.). Talking Glossary of Genetic Terms. Retrieved February 17, 2005 from <http://www.genome.gov/10002096>

- 
- <sup>66</sup> U.S. Department of Energy, Human Genome Project (January 12, 2004) Genome Glossary. Retrieved February 17, 2005 from [http://www.ornl.gov/sci/techresources/Human\\_Genome/glossary/](http://www.ornl.gov/sci/techresources/Human_Genome/glossary/)
- <sup>67</sup> National Library of Medicine, Genetics Home Reference, Your Guide to Understanding Genetic Conditions (February 11, 2005). Retrieved February 17, 2005 from <http://ghr.nlm.nih.gov/ghr/glossary/Glossary.jsessionid=FD02D1BEFA70709B6D9E24B04996C6F7>
- <sup>68</sup> GeneTests (May 18, 2004).[database] Retrieved February 17, 2005 from <http://www.genetests.org/servlet/access?qry=ALLTERMS&db=genestar&fcn=term&gtreport2=true&id=17563&key=i3UZrab5qemYo>
- <sup>69</sup> Access Excellence, National Health Museum (n.d.) Structure of the DNA Molecule Glossary. Retrieved February 17 2005 from [http://www.accessexcellence.org/AE/AEC/CC/DNA\\_glossary.html](http://www.accessexcellence.org/AE/AEC/CC/DNA_glossary.html)
- <sup>70</sup> Johnson, V.P., Christiansen, C., University of Iowa, Virtual Childrens Hospital (n.d.) Clinical Genetics: A Self Study for Health Care Providers. Glossary of Abbreviations. Retrieved February 17, 2005 from <http://www.vh.org/pediatric/provider/pediatrics/ClinicalGenetics/AppendixB/AppenBGlossofAbbrev.html>
- <sup>71</sup> National Human Genome Research Institute (n.d.) Policy and Legislation Database. [database] Retrieved February 17, 2005 from <http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm>
- <sup>72</sup> U.S. Department of Energy, Human Genome Project (September 16, 2004), Genetics and Patenting. Retrieved February 17, 2005 from [http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/patents.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/patents.shtml)
- <sup>73</sup> North Carolina Center for Genomics and Public Health (n.d.) The Genomics Revolution and Public Health, Policy Issues in Genetic Testing [webcast] Retrieved February 17, 2005 from <http://www.sph.unc.edu/nccgph/phgenetics/video.htm>
- <sup>74</sup> McGee, G., Action Bioscience (February 2001): Primer on Ethics and Human Cloning. Retrieved February, 17, 2005 from <http://www.actionbioscience.org/biotech/mcgee.html>
- <sup>75</sup> American Academy of Pediatrics, Committee on Bioethics (June 2001) Ethical Issues with Genetic Testing in Pediatrics. *Pediatrics* [Electronic version] 107(6): 1451-1455. Retrieved February 17, 2005 from <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;107/6/1451.pdf>

- 
- <sup>76</sup> National Human Genome Research Institute (September, 2004). Direct to consumer marketing of genetic tests [Workshop summary held March 23, 2004]. Retrieved February 17, 2005 from <http://www.genome.gov/12010659>
- <sup>77</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention (December 2, 2004). Ethical, Legal and Social Issues (ELSI). Retrieved February 17, 2005 from <http://www.cdc.gov/genomics/links/ethical.htm>
- <sup>78</sup> Maternal and Child Health Bureau, Health Resources Service Administration; Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children. [Archived Presentations]. Retrieved February 17, 2005 from <http://mchb.hrsa.gov/programs/genetics/committee/>
- <sup>79</sup> Public Health Program Planning Office, Centers for Disease Control and Prevention, Public Health Training Network (April 23, 2003): A New Era in Newborn Screening: Saving Lives, Improving Outcomes [Webcast from 2002]. Retrieved February 17, 2005 from <http://www.phppo.cdc.gov/PHTN/webcast/newborn/default.asp>
- <sup>80</sup> Genetic Science Learning Center, University of Utah (2003): Newborn Genetic Screening, What Should We Test and Why? Retrieved February 17, 2005 from <http://gslc.genetics.utah.edu/teachers/units/newborn/NGS-student%20packet.pdf>
- <sup>81</sup> North Carolina Department of Health and Human Services, North Carolina State Laboratory for Public Health (n.d.) Newborn Screening. Retrieved February 17, 2005 from <http://slph.state.nc.us/Newborn/default.asp>
- <sup>82</sup> March of Dimes, Pregnancy and Newborn Health Education Center.(n.d.) Newborn Screening for Genetic Disorders. Retrieved February 17, 2005 from [http://marchofdimes.com/pnhec/298\\_834.asp](http://marchofdimes.com/pnhec/298_834.asp)
- <sup>83</sup> National Newborn Screening and Genetic Resource Center, University of Texas Health Science Center at San Antonio Newborn Screening Resources (January 21, 2005). Retrieved February 17, 2005 from <http://genes-r-us.uthscsa.edu/index.htm>
- <sup>84</sup> Mountain States Genetics Network. Newborn Screening Practitioners Manual (October, 2003). Retrieved February 17, 2005 from <http://www.mostgene.org/pract/praclist.htm>
- <sup>85</sup> Johnson, V.P., Christiansen, C., University of Iowa, Virtual Childrens Hospital (n.d.). from Clinical Genetics, A Self Study Guide for Health Professionals, A Glossary of Malformations. Retrieved February 17, 2005 from <http://www.vh.org/pediatric/provider/pediatrics/ClinicalGenetics/AppendixB/AppendixBGlossMalf.html>

---

<sup>86</sup> National Conference of State Legislators, Genetics Technology Project (2004) Retrieved February 17, 2005 from <http://www.ncsl.org/programs/health/genetics/nbs.htm>

<sup>87</sup> Grosse, S.D., Boyle, C.A., Botkin, J.R. et al. Centers for Disease Control and Prevention, Morbidity Mortality Weekly Reports (October 15, 2004). Newborn Screening for Cystic Fibrosis-Evaluation of Benefits, Risks and Recommendations for State Newborn Screening Programs [Electronic version]. 53(RR13):1-36. Retrieved February 17, 2005 from <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5313a1.htm>

<sup>88</sup> National Cancer Institute. Cancer Facts (August 10, 2000). Questions and Answers on Estimating Cancer Risk in Ashkenazi Jews. Retrieved February 17, 2005 from [http://cis.nci.nih.gov/fact/3\\_60.htm](http://cis.nci.nih.gov/fact/3_60.htm)

<sup>89</sup> Cooper, R., North Carolina Center for Genomics and Public Health (2003) Molecular Genetics, Race and Health [Webcast] Retrieved February 17, 2005 from [http://www.sph.unc.edu/nccgph/presentations/pres\\_cooperwebcast.htm](http://www.sph.unc.edu/nccgph/presentations/pres_cooperwebcast.htm)

<sup>90</sup> Rotimi, C.N., University of North Carolina, School of Public Health, Minority Health Project (June 10, 2003) Genomic Definition of Self and Group Identity: Implications for Biomedical Research [Webcast]. Retrieved February 17, 2005 from [http://www.sph.unc.edu/about/webcasts/2003-06-10\\_mhc/view\\_webcast\\_archive.cfm](http://www.sph.unc.edu/about/webcasts/2003-06-10_mhc/view_webcast_archive.cfm)

<sup>91</sup> Spice, B., (May 7, 2002). Genetics and Race: Researchers Explore Why Rates of Diseases Vary From One Population to Another. Pittsburg Post Gazette [Electronic version]. Retrieved February 17, 2005 from <http://www.post-gazette.com/healthscience/20020507hgene0507p3.asp>

<sup>92</sup> Grody, W.W., Cutting, G.R., Klinger, K.W., Richard, C.S., Watson, M.S., & Desnick, R.J., (2001). American College of Medical Genetics [Consensus Conference] Laboratory Standards and Guidelines for Population-Based Cystic Fibrosis Carrier Screening. [Electronic version]. *Genetics in Medicine* 3(2):149-54. Retrieved February 17, 2005 from <http://www.acmg.net/resources/policies/pol-005.asp>

<sup>93</sup> National Institute of General Medical Sciences, National Institutes of Health, Publication 01-5021, (December, 2001) Genes and Populations. Retrieved February 17, 2005 from [http://www.nigms.nih.gov/news/science\\_ed/genepop/](http://www.nigms.nih.gov/news/science_ed/genepop/)

<sup>94</sup> Plaisted, D.A., University of North Carolina, Department of Computer Sciences (n.d.). Population Genetics Made Simple. Retrieved February 17, 2005 from <http://www.cs.unc.edu/~plaisted/ce/genetics.html>



---

<sup>95</sup> National Cancer Institute, National Institutes of Health (June 16, 2004). Cancer Genetics Overview. Retrieved February 17, 2005 from <http://www.nci.nih.gov/cancertopics/pdq/genetics/overview>

<sup>96</sup> National Cancer Institute, National Institutes of Health (December 21, 2004). Genetics of Breast and Ovarian Cancer. Retrieved February 17, 2005 from <http://www.nci.nih.gov/cancertopics/pdq/genetics/breast-and-ovarian>

<sup>97</sup> National Cancer Institute, National Institutes of Health (January 13, 2005). Genetics of Colorectal Cancer. Retrieved February 17, 2005 from <http://www.nci.nih.gov/cancertopics/pdq/genetics/colorectal>

<sup>98</sup> Genetic Solutions (January 11, 2005). Case: Family History of Colorectal Cancer. Retrieved March 3, 2005 from <http://www.geneticsolutions.com/PageReq?id=499:13500>

<sup>99</sup> National Cancer Institute, National Institutes of Health (September 17, 2004). Genetics of Prostate Cancer. Retrieved February 17, 2005 from <http://www.nci.nih.gov/cancertopics/pdq/genetics/prostate>

<sup>100</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention (October 19, 2004). Genetics and Obesity: A Public Health Perspective. Retrieved February 17, 2005 from <http://www.cdc.gov/genomics/info/perspectives/obesity.htm>

<sup>101</sup> Washington Center for Genomics and Public Health, University of Washington (October 14, 2004). Genetics of Obesity. Retrieved February 17, 2005 from <http://depts.washington.edu/cgph/centergoals/obesity.htm>

<sup>102</sup> American Diabetes Association (n.d.). The Genetics of Diabetes. Retrieved February 17, 2005 from <http://www.diabetes.org/genetics.jsp>

<sup>103</sup> National Institute of Diabetes & Digestive & Kidney Diseases, National Center for Biotechnology Information (July 7, 2004). The Genetic Landscape of Diabetes. Retrieved February 17, 2005 from <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?call=bv.View..ShowTOC&rid=diabetes.TOC&depth=2>

<sup>104</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention (October 15, 2004). Asthma Genomics, Implications for Public Health; A Public Health Perspective. Retrieved February 17, 2005 from <http://www.cdc.gov/genomics/info/perspectives/asthma.htm>

- 
- <sup>105</sup> Discovery Channel, Discovery Health (July 16, 2000). The Genetics of Asthma. Retrieved February 17, 2005 from <http://health.discovery.com/minisites/dna/asthma.html>
- <sup>106</sup> Lifton, R.P., Seidman, C.E. Howard Hughes Medical Institute, BioInteractive, Holiday Lectures on Science (1998). Of Hearts and Hypertension- Blazing a Genetic Trail. [Webcast ]. Retrieved March 3, 2005 from <http://www.hhmi.org/biointeractive/cardiovascular/lectures.html>
- <sup>107</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention (August 2000). Gene-Environment Interactions Fact Sheet. Retrieved February 17, 2005 from <http://www.cdc.gov/genetics/info/files/text/GeneEnviro.pdf>
- <sup>108</sup> Sternesky, L., Association of State and Territorial Health Officials (June 2002). Genes and the Environment Issue #3 [Brief]. Retrieved February 17, 2005 from <http://www.astho.org/pubs/GenesandEnvironmentFINAL.pdf>
- <sup>109</sup> National Center for Biotechnology Information (March 31, 2004). One Size Does Not Fit All: The Promise of Pharmacogenomics [Science Primer]. Retrieved February 17, 2005 from <http://www.ncbi.nlm.nih.gov/About/primer/pharm.html>
- <sup>110</sup> National Institute of General Medical Sciences, National Institutes of Health (n.d.). Medicines for You. Retrieved February 17, 2005 from <http://www.nigms.nih.gov/funding/medforyou.html>
- <sup>111</sup> Roses, A.D., (2000). Pharmacogenetics and the Practice of Medicine. *Nature* [Electronic version]. June, 15, 2005 [www.nature.com](http://www.nature.com) Retrieved February 17, 2005 from <http://genetics.gsk.com/docs/RosesNature.pdf>
- <sup>112</sup> Renegar, G., Reiser, P., and Manasco, P., (2001). Pharmacogenetics: the Rx Perspective [Electronic version]. *Future-Drugs: Exp Rev Mol Diagn*, 1(3):89-97. Online at: [www.future-drugs.com](http://www.future-drugs.com). Retrieved February 17, 2005 from <http://genetics.gsk.com/docs/Manascob.pdf>
- <sup>113</sup> Kurth, J.H., American Association for Clinical Chemistry (n.d.) Pharmacogenetics: A Prescription for Industry? [slide set] Retrieved February 17, 2005 from <http://www.aacc.org/access/pharmacogenomics/>
- <sup>114</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention (February 23, 2005). Family History for Preventive Medicine and Public Health. Retrieved March, 3, 2005 from <http://www.cdc.gov/genomics/activities/famhx.htm>
- <sup>115</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention (February 23, 2005). Family History as a Tool for Public Health and

---

Preventive Medicine: A Public Health Perspective. Retrieved March 3, 2005 from <http://www.cdc.gov/genomics/info/perspectives/famhistr.htm>

<sup>116</sup> National Society of Genetic Counselors. (n.d.). Your Family History-Your Future. Retrieved March 3, 2005 from <http://www.nsgc.org/consumer/familytree/index.asp>

<sup>117</sup> U.S. Department of Health and Human Services, Office of the Surgeon General (December 29, 2004) My Family Health Portrait. [Family History Software]. Retrieved March 3, 2005 from <http://www.hhs.gov/familyhistory/>

<sup>118</sup> American Medical Association (March, 25, 2005). Family History Tools. Retrieved March 27, 2005 from <http://www.ama-assn.org/ama/pub/category/2380.html>

<sup>119</sup> Genetics Education Program for Nurses, University of Cincinnati, Children's Hospital (n.d.). Interpreting Family History. Retrieved March 3, 2005 from <http://www.cincinnatichildrens.org/ed/clinical/gpnf/ce/skill/default.htm>

<sup>120</sup> Comprehensive Cancer Center, Arthur G. James Cancer Hospital, Ohio State University (n.d.). Cancer Genetics Workbook, Building and Understanding Your Medical Family History. Retrieved March 3, 2005 from <http://www.jamesline.com/patientsandpublic/prevention/cancergeneticsworkbook/>

<sup>121</sup> American Academy of Family Practice, Annual Clinical Focus (2005), Family History [video program]. Retrieved March 3, 2005 from <http://www.aafp.org/x30165.xml>  
(Notes: CME credit available, requires RealPlayer)

<sup>122</sup> Penson, R.T., Seiden, M.V., Shannon, K.M., Lubratovich, M.C., Roche, M., Chabner, B.A., et al. (2000). Communicating Genetic Risk: Pro's Cons and Counsel [Electronic version]. The Oncologist, 5(2):152-161. Retrieved March 3, 2005 from <http://theoncologist.alphamedpress.org/cgi/reprint/5/2/152>

<sup>123</sup> National Cancer Institute (October, 20, 2004). Cancer Genetics Risk Assessment and Counseling. Retrieved March 3, 2005 from <http://www.cancer.gov/cancerinfo/pdq/genetics/risk-assessment-and-counseling>

<sup>124</sup> National Cancer Institute (n.d.). Cancer Genetics Service Directory. Retrieved March 3, 2005 from <http://www.cancer.gov/search/geneticsservices/>

<sup>125</sup> Harvard Center for Cancer Prevention (n.d.). Colorectal Cancer: A Risk Management Guide for Health Care Professionals. Retrieved March 3, 2005 from [http://www.hsph.harvard.edu/cancer/crc/downloads/CRC\\_guide.pdf](http://www.hsph.harvard.edu/cancer/crc/downloads/CRC_guide.pdf)

<sup>126</sup> Harvard Center for Cancer Prevention (June 2004). What's Your Disease Risk? Retrieved March 3, 2005 from <http://www.yourdiseaserisk.harvard.edu/>

- 
- <sup>127</sup> GeneticSolutions (December 13, 2004). Introduction to Genetic Counseling. Retrieved March 3, 2005 from <http://www.geneticsolutions.com/PageReq?id=675:8758>
- <sup>128</sup> GeneTests (March 19, 2004). About Genetics Services. Retrieved March 3, 2005 from <http://www.geneclinics.org/servlet/access?id=8888892&key=z mz5f4T8wEeK2&f cn=y&fw=yeoL&filename=/concepts/primer/primerintro.html>
- <sup>129</sup> National Society of Genetic Counselors (n.d.). ResourceLink. Retrieved March 3, 2005 from <http://www.nsgc.org/resourcelink.asp>
- <sup>130</sup> Mountain States Genetics Network (n.d.). Indications for Genetic Counseling Referrals. Retrieved March 3, 2005 from <http://www.mostgene.org/dir/indicate.htm>
- <sup>131</sup> University of Medicine and Dentistry of New Jersey (February 2002). Indicators for Genetic Service Referral. Retrieved March 3, 2005 from [http://www.umdj.edu/genesatwork/clinicalserv/02\\_indicators\\_genetic.htm](http://www.umdj.edu/genesatwork/clinicalserv/02_indicators_genetic.htm)
- <sup>132</sup> GlaxoSmithKline (n.d.). Genetics at GlaxoSmithKline Retrieved March 3, 2005 from <http://genetics.gsk.com/healthcare.htm>
- <sup>133</sup> GlaxoSmithKline (n.d.). Understanding Genetics [multimedia]. Retrieved March 3, 2005 from [http://genetics.gsk.com/generalpublic\\_flash.htm](http://genetics.gsk.com/generalpublic_flash.htm)
- <sup>134</sup> Roche Laboratories (n.d.). Clinical Genetics. [multimedia]. Retrieved March 3, 2005 from [http://www.roche.com/home/science/sci\\_gengen/sci\\_gengen\\_cdrom.htm](http://www.roche.com/home/science/sci_gengen/sci_gengen_cdrom.htm)
- <sup>135</sup> McCabe, E., Dartmouth Medical School, Interactive Media Lab (July 2, 2004). Genetics in Clinical Practice: A Team Approach. Retrieved March 3, 2005 from <http://www.iml.dartmouth.edu/education/cme/Genetics/>
- <sup>136</sup> Cincinnati Children's Medical Center, Genetics Education Program for Nurses (n.d.). Mendelian Inheritance-Meiosis Connection. Retrieved March 3, 2005 from <http://www.cincinnatichildrens.org/ed/clinical/gpnf/resources/curriculum/mendelian.htm>
- <sup>137</sup> Dolan DNA Learning Center, Cold Spring Harbor Laboratories (n.d.). Your Genes Your Health. Retrieved March 3, 2005 from <http://www.ygyh.org>
- <sup>138</sup> Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention. Genomics for Public Health Practitioners (February 23, 2004) [multimedia]. Retrieved March 3, 2005 from <http://www.cdc.gov/genomics/training/GPHP/default.htm>

- 
- <sup>139</sup> Michigan Center for Genomics and Public Health (Aug 24, 2004) Six Weeks to Genomic Awareness [powerpoint presentations]. Retrieved March 3, 2005 from <http://www.genomicawareness.org/index.htm>
- <sup>140</sup> Dolan DNA Learning Center (n.d.). Biology Animation Library. Retrieved March 3, 2005 from <http://www.dnalc.org/resources/BiologyAnimationLibrary.htm>
- <sup>141</sup> Science Museum. Dolly the Sheep 1997-2003 (n.d.). [Online museum exhibit]. Retrieved March 3, 2005 from <http://www.sciencemuseum.org.uk/antenna/dolly/index.asp>
- <sup>142</sup> Braun, D., National Geographic News. (February 14, 2002). Scientists Successfully Clone Cat. Retrieved March 3, 2005 from [http://news.nationalgeographic.com/news/2002/02/0214\\_021402copicat.html](http://news.nationalgeographic.com/news/2002/02/0214_021402copicat.html)
- <sup>143</sup> National Center for Biotechnology Information (n.d.). Online Mendelian Inheritance in Man (OMIM) [database]. Retrieved March 3, 2005 from <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM>
- <sup>144</sup> Schindler, L., Kerrigan, D., & Kelly J., National Cancer Institute (January 28, 2005). Understanding Gene Testing. [Slide series]. Retrieved March 3, 2005 from <https://cissecure.nci.nih.gov/ncipubs/details.asp?pid=231>
- <sup>145</sup> From Access Excellence, National Health Museum (n.d.) Understanding Gene Testing. Retrieved March 3, 2005 from <http://www.accessexcellence.org/AE/AEPC/NIH/gene27.html>
- <sup>146</sup> Toland, A.E., GeneticHealth: (August 25, 2000) Genetic Testing, Case Study- The Testing Process. Retrieved March 3, 2005 from [http://www.genetichealth.com/GT\\_Genetic\\_Testing\\_Case\\_Study\\_The\\_Testing\\_Process.shtml](http://www.genetichealth.com/GT_Genetic_Testing_Case_Study_The_Testing_Process.shtml)
- <sup>147</sup> Yoon, P.W., Chen, B., Faucett, A., Clyne, M., Gwinn, M., Lubin, I.M., et al. (2001). Public Health Impact of Genetic Tests at the End of the 20<sup>th</sup> Century [Electronic version]. *Genetics in Medicine* 3(6): 405-410. Retrieved March 3, 2005 from <http://www.cdc.gov/genomics/info/reports/files/print/gim3-6-405.pdf>
- <sup>148</sup> Genetics and Public Policy Center, Johns Hopkins University (January 8, 2004) [Webcast] - Custom Kids: Genetic Testing of Embryos: A Policy Forum on Preimplantation Genetic Diagnosis. Retrieved March 3, 2005 from [http://www.intellor.com/genetics/index\\_DHTML.html?gLanguage=EN&gBitrate=384&gFormat=Mix\\_cAssetWM](http://www.intellor.com/genetics/index_DHTML.html?gLanguage=EN&gBitrate=384&gFormat=Mix_cAssetWM)

- 
- <sup>149</sup> Hudson, K., Genetics and Public Policy Center. Johns Hopkins University (n.d.). Reproductive Genetic Testing: Issues and Options for Policymakers. Retrieved March 3, 2005 from <http://tools-content.labvelocity.com/pdfs/5/66755.pdf>
- <sup>150</sup> Michigan Center for Genomics and Public Health (n.d.). Retrieved March 3, 2005 from <http://www.sph.umich.edu/genomics/index.html>
- <sup>151</sup> Washington Center for Genomics and Public Health (n.d.). Retrieved March 3, 2005 from <http://depts.washington.edu/cgph/>
- <sup>152</sup> Coalition of State Genetics Coordinators (n.d.). Retrieved March 3, 2005 from <http://www.stategeneticscoordinators.org/index.html>
- <sup>153</sup> Division of Public Health, Office of Genomics. (January, 2004). North Carolina Public Health Genomics Plan. Retrieved March 3, 2005 from <http://www.communityhealth.dhhs.state.nc.us/Genomics/Annual%20Report.pdf>
- <sup>154</sup> Gwinn, M., Bedrosian, S., Ottmann, D., & Khoury, M.J., Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention (March 2004). Genomics and Population Health: United States 2003. Atlanta, GA; 2004. Retrieved March 3, 2005 from <http://www.cdc.gov/genomics/activities/ogdp/2003.htm>
- <sup>155</sup> University of North Carolina, School of Public Health (May 4, 2000). Genetics and Public Health: the Future is Now. [Webcast]. Retrieved March 3, 2005 from <http://www.publichealthgrandrounds.unc.edu/genetics/index.htm>
- <sup>156</sup> University of North Carolina, School of Public Health, North Carolina Center for Genomics and Public Health. (n.d.). The Genomics Revolution and Public Health [Webcast]. Retrieved March 3, 2005 from <http://www.sph.unc.edu/nccgph/phgenetics/index.htm>
- <sup>157</sup> Association of State and Territorial Health Officials. Genomics: A Guide for Public Health (n.d.). Retrieved March 3, 2005 from <http://www.genomicstoolkit.org/index.shtml>
- <sup>158</sup> Public Health Foundation, Training Finder Real-Time Affiliated Integrated Network; TRAIN [database]. Retrieved March 3, 2005 from <https://www.train.org/DesktopShell.aspx>
- <sup>159</sup> North Carolina Institute of Public Health, Southeast Public Health Training Center [database]. AskSphere (Southeast Public Health Educational Resource for Enhancement). Retrieved March 3, 2005 from <http://www.asksphere.org/>

